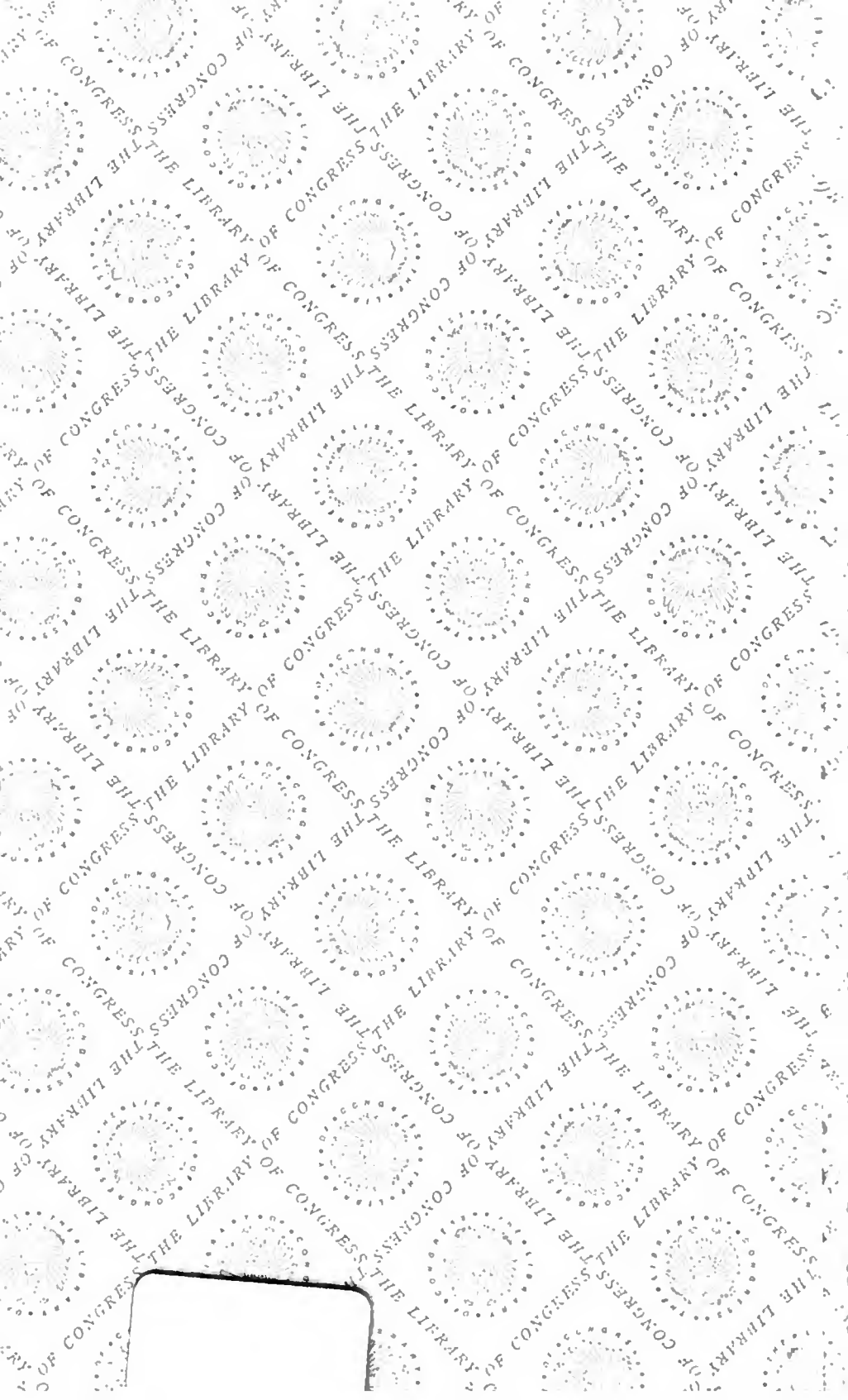

ARTHRITIS PREVENTION, TREATMENT, AND REHABILITATION

HEARING

BEFORE THE

SUBCOMMITTEE ON PUBLIC HEALTH AND ENVIRONMENT

United States. Congress.
" House.

OF THE

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

HOUSE OF REPRESENTATIVES

NINETY-THIRD CONGRESS

SECOND SESSION

ON

H.R. 12150, H.R. 14181, and S. 2854
(and all identical bills)

BILLS TO AMEND THE PUBLIC HEALTH SERVICE ACT SO AS TO EXPAND THE AUTHORITY OF THE NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES IN ORDER TO ADVANCE A NATIONAL ATTACK ON ARTHRITIS, AND FOR OTHER PURPOSES

NOVEMBER 25, 1974

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ARTHRITIS PREVENTION, TREATMENT, AND REHABILITATION

MONDAY, NOVEMBER 25, 1974

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON PUBLIC HEALTH AND ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met at 2 p.m., pursuant to notice, in room 2123, Rayburn House Office Building, Hon. Paul G. Rogers (chairman) presiding.

Mr. ROGERS. The subcommittee will come to order, please.

The hearings today are on H.R. 12150, the National Arthritis Act, introduced by Mr. Staggers, H.R. 14181, the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974, as sponsored by Dr. Carter, myself, and most of the other members of the subcommittee, as well as other bills, to launch a major attack on arthritis and related musculoskeletal diseases. S. 2854, similar legislation, has passed the Senate. I hope we will be able to report out legislation on this subject in time for passage this session.

We are pleased to have with us today Dr. Henry Simmons of the Department of HEW; Dr. Whedon, who is Director of the National Institute of Arthritis, Metabolism, and Digestive Diseases; and Mr. Sopper of the Legislative Office; and, of course, the distingnished panel of rheumatologists, orthopedic surgeons, and occupational therapy professionals. We welcome all of you here today.

Arthritis in its various forms, I think everyone knows, has disabled 3½ million Americans and claims about 250,000 new victims each year. It is estimated that 50 million Americans have arthritis, 20 million of whom require medical attention. It affects the yonng as well as the old. The annual impact of arthritis is more than $9 billion per year, $2½ billion of which is costs of medical treatment annually. We must step up our efforts to devise better methods of prevention, treatment, and rehabilitation of arthritis in order to lower the cost of treatment and relieve the suffering of those persons afflicted.

The Federal Government at NIH at present is contribnting about $14 million for research on arthritis, and this is shocking considering the large number of victims and the economic losses resulting to the economy due to disabling effects of the disease.

It is my understanding that NIH is spending nothing on intramural orthopedic research within the Institute. This is an area offering great promise for treatment of isteoarthritis, which alone afflicts about 12 million of the 20 million persons afflicted with all forms of the disease.

Also there are only about 2,000 rheumatologists in the United States to take care of about 20 million patients, and over 40 of the country's 115 medical schools offer no training in rheumatology.

It is envisioned that the legislation we have introduced will help this situation by establishing arthritis research, treatment, and training centers, would provide an additional boost to the training and graduate medical students interested in arthritis.

We hope to correct the shortcomings in the Government's arthritis program in the shortest possible time and give this area of health, research, and care the priority it deserves. If at all possible, I would like to see something in this session of the Congress.

The text of H.R. 12150, H.R. 14181, the Senate-passed version, S. 2854, and all identical bills and the agency reports thereon shall be placed in the record at this time without objection.

[Testimony resumes on p. 61.]

[Text of H.R. 12150, H.R. 14181, S. 2854, and all identical bills and the agency reports thereon follow:]

[H.R. 12150, introduced by Mr. Staggers on December 22, 1974; H.R. 12340, introduced by Mr. Hammerschmidt on January 29, 1974; H.R. 12943, introduced by Mrs. Boggs on February 21, 1974 and H.R. 14008, introduced by Mr. Howard on April 4, 1974, are identical as follows:]

A BILL

To amend the Public Health Service Act so as to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That the Act may be cited as the "National Arthritis Act".

FINDINGS AND DECLARATIONS OF PURPOSE

SEC. 2. (a) The Congress hereby finds and declares that—

(1) arthritis and related museuloskeletal and other related diseases represent one of the most serious and widespread health problems in the United States in that they afflict more than twenty million Americans;

(2) arthritis is the greatest single cause of chronic pain and disability;

(3) the complications of arthritis lead to many other serious health problems;

(4) uncontrolled arthritis significantly decreases the quality of life and has a major negative economic, social, and psychological impact on the families of its victims and society generally;

(5) the severity of arthritis in children and most adolescents is greater than in adults and this involves greater problems in the management of the disease;

(6) athletic and other types of joint injuries can lead to arthritis;

(7) the annual cost to the national economy in 1970 due to arthritis, in medical care bills and lost wages, was $9,200,000,000;

(8) the workdays lost due to disability caused by arthritis totaled over 14,500,000 in 1970;

(9) although today's currently available therapy and surgical techniques for improving the functional state of millions of arthritics are significantly more effective than those of a decade ago, they remain stop-gap measures which neither prevent nor cure the disease; and therefore the attainment of better methods of diagnosis and treatment of arthritis through research

and through education of health professionals and allied health professionals deserves the highest national priority;

(10) there are inadequate numbers of medical facilities and of properly trained personnel to provide treatment and rehabilitation of persons suffering from arthritis, and inadequate numbers of properly trained personnel to train other health personnel interested in pursuing neither a research or clinical career in rheumatology;

(11) the citizens of the United States should have a full understanding of the nature of the human, social, and economic impact of arthritis and should be encouraged to seek early diagnosis and treatment to prevent or lessen disability resulting from arthritis; and

(12) there is great potential for making major advances against arthritis in the National Institute of Arthritis, Metabolism, and Digestive Diseases, in concert with other Institutes of the National Institutes of Health, and public and private organizations capable of necessary research and public education in arthritis.

(b) It is therefore the purpose of this Act to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis.

NATIONAL ARTHRITIS PROGRAM

SEC. 3. Part D of title IV of the Public Health Service Act is amended by adding after section 434 the following new sections:

"NATIONAL TASK FORCE ON ARTHRITIS

"SEC. 435. (a) The Secretary, within sixty days after the date of enactment of this section, shall establish a National Task Force on Arthritis (hereinafter in this part referred to as the 'Task Force') to formulate a long-range plan (hereinafter in this part referred to as the 'Arthritis Plan') to combat arthritis and related musculoskeletal and other related diseases (hereinafter in this part referred to as 'arthritis'). The Arthritis Plan shall include recommendations for the utilization and organizations of national resources for the campaign against arthritis, and a program for the National Institute of Arthritis, Metabolism, and Digestive Diseases (hereinafter in this part referred to as the 'Institute') as a major participant in the campaign against arthritis.

"(b) The Arthritis Plan developed by the Task Force shall provide for—

"(1) programs for investigation into the epidemiology, etiology, and prevention and control of arthritis, including investigation into the social, environmental, behavioral, nutritional, biological, and genetic

determinants and influences involved in the epidemiology, etiology, prevention, and control of arthritis;

"(2) studies and research into the basic biological processes and mechanisms involved in the underlying normal and abnormal phenomena associated with arthritis, including, but not limited to, abnormalities of the immune, musculoskeletal, cardiovascular, and nervous systems, the skin, the gastrointestinal tract, the kidneys, the lungs, and the eyes;

"(3) research into the development, trial, and evaluation of techniques, including surgical procedures and drugs, used in, and approaches to, the diagnosis, early detection, treatment, prevention, and control of arthritis;

"(4) establishment of programs that will focus and apply scientific and technological methodologies and processes involving biological, physical, and engineering science to deal with all facets of arthritis, including traumatic arthritis;

"(5) establishment of programs for the conduct and direction of field studies, large-scale testing, evaluation, and demonstration of preventive, diagnostic, therapeutic, rehabilitative, and control approaches to arthritis, including studies of the effectiveness of home care programs, the use of mobile care units, community reha-

bilitation facilities, and other appropriate community public health and social services;

"(6) studies of the feasibility and possible benefits accruing from team training of health and allied health professionals in the treatment and rehabilitation of individuals suffering from arthritis;

"(7) programs to evaluate the current resources for the rehabilitation of the arthritis patient and establish criteria for the potential for rehabilitation of the patient;

"(8) programs to investigate alternative screening possibilities to define more adequately the arthritis population and to detect early cases of rehabilitative arthritis;

"(9) programs for the education and training of scientists, bioengineers, clinicians, surgeons, including orthopedic surgeons, and other health and allied health professionals and educators in the fields and specialties requisite to the conduct of programs regarding arthritis;

"(10) programs for the continuing education of health and allied health professionals in the diagnosis, treatment, and rehabilitation of individuals suffering from arthritis;

"(11) programs for public education relating to all aspects of arthritis;

"(12) programs to establish standards of measure-

ment of the severity of disabilities resulting from arthritis;

"(13) the development of a common descriptive vocabulary in basic and clinical research in arthritis for the purpose of standardizing collection, storage, and retrieval of research and treatment data to facilitate collaborative and comparative studies of large patient populations;

"(14) the development of a national data storage bank on arthritis research, diagnosis, prevention, control, and treatment to collect and make available information as to the practical application of research and other activities pursuant to this part; and

"(15) a plan for international cooperation in and exchange of knowledge on all aspects of research, diagnosis, treatment, prevention, and control of arthritis.

"(c) The Task Force shall be composed of sixteen members who are eminently qualified to serve on such Task Force, as follows:

"(1) the Secretary or his designee, the Director of the National Institutes of Health or his designee, the Associate Director for Arthritis of the Institute (as established by section 436), the Chief Medical Director of the Veterans' Administration, and the Secretary of

Defense or his designee, who shall serve as ex officio members;

"(2) seven members who shall be scientists or physicians representing the various specialties and disciplines pertinent to arthritis, of whom at least two are practicing clinical rheumatologists;

"(3) three members from the general public, of whom at least two are arthritis sufferers; and

"(4) one member of the National Arthritis, Metabolism, and Digestive Diseases Advisory Council (hereinafter referred to as the National Advisory Council) whose primary interest is in the field of rheumatology.

"(d) The Secretary shall designate one member of the Task Force as Chairman of the Task Force. The Task Force shall first meet at the call of the Secretary, and thereafter at the call of the Chairman of the Task Force, and shall meet not less than 3 times.

"(e) (1) The Task Force shall publish and transmit to the Director of the Institute the Arthritis Plan not later than nine months after the date of enactment of this section.

"(2) Not later than sixty days after the Task Force transmits the Arthritis Plan to the Director of the Institute, the Director shall submit to Congress the Arthritis Plan, his proposals for Institute activities under this part for the first

five years under the Arthritis Plan, and an estimate of such additional staff positions and appropriations (including increased appropriations authorizations) as may be required to carry out such activities. If the plan and subsequent reports to be submitted pursuant to subsections (c) (1) and (2) of this section are submitted, prior to submission to the Congress, for review by the Office of Management and Budget or any other Federal department or agency or official thereof, (1) the plan or report submitted to the Congress shall specify the changes and the reasons therefor made during any such review process, and (2) if any such review process delays the submission of such plan or report to the Congress beyond the date established for such submission by this section, the Director shall immediately on such date submit to the Congress the plan or report in exactly the form it was submitted to such review process.

"(f) The Task Force may hold such hearings, take such testimony, and sit and act at such times and places as the Task Force deems advisable to develop the Arthritis Plan.

"(g) The Director of the Institute shall—

"(1) designate a member of the staff of such Institute to act as Executive Secretary of the Task Force; and

"(2) provide the Task Force with such full-time professional and clerical staff, such information, and the

services of such consultants, as may be necessary to assist the Task Force to carry out effectively its functions under this section.

"(h) Members of the Task Force who are not officers or employees of the United States shall receive for each day they are engaged in the performance of the functions of the Task Force compensation at rates not to exceed the daily equivalent of the annual rate in effect for grade GS–18 of the General Schedule, including traveltime; and all members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by section 5703, title 5, United States Code, for persons in the Government service employed intermittently.

"(i) In addition to sums appropriated pursuant to section 301 and other sums appropriated for research on arthritis pursuant to title IV, part D, there is authorized to be appropriated $500,000 for the fiscal year ending June 30, 1974, and June 30, 1975, to carry out the purposes of this section, and such sums shall remain available until expended.

"ASSOCIATE DIRECTOR FOR ARTHRITIS AND ESTABLISHMENT OF COMMITTEES

"SEC. 436. (a) There is established within the Institute the position of Associate Director for Arthritis (hereinafter in this part referred to as the 'Associate Director'), who

shall report directly to the Director of such Institute and who, under the supervision of the Director of such Institute, shall be responsible for programs regarding arthritis within such Institute.

"(b) In order to improve coordination of the total National Institutes of Health research activities relating to arthritis, the Director of the National Institutes of Health shall establish an Inter-Institute Arthritis Coordinating Committee to be composed of representatives who can make policy commitments for each of the Institutes and divisions involved in arthritis-related research. The committee will be chaired by the Associate Director and will prepare a report as soon (but not later than 60 days) after the end of each fiscal year as possible for the Director of the National Institutes of Health detailing the work of the committee in coordinating the research activities of the National Institutes of Health relating to arthritis during the preceding year.

"(c) (1) There is established within the Federal Government an Interagency Technical Committee on Arthritis which shall be responsible for promoting the coordination of those aspects of all Federal health programs and activities relating to arthritis to assure the adequacy and technical soundness of such programs and activities and to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities.

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(2) The Director and Associate Director for Arthritis of the Institute shall serve as Chairman and Cochairman, respectively, of such Committee, and such Committee shall include representation from the Veterans' Administration, the Department of Defense, and all other Federal departments and agencies administering programs involving health functions or responsibilities as determined by the Secretary.

"(3) The Committee shall meet at the call of the chairman, but not less often than four times a year.

"ARTHRITIS SCREENING, EARLY DETECTION, PREVENTION, AND CONTROL PROGRAMS

"SEC. 437. (a) The Director of the Institute under policies established by the Director of the National Institutes of Health, and after consultation with the National Advisory Council and consistent with the Arthritis Plan, shall establish programs as necessary for cooperation with other Federal health agencies, State, local, and regional public health agencies, and nonprofit private health agencies, in the screening, detection, prevention, and control of arthritis which emphasize the development of new diagnostic and treatment methods for arthritis, and the dissemination of the knowledge about these methods to the health professions.

"(b) Screening, detection, prevention, and control programs under this part shall include—

"(1) programs to develop improved methods of detecting individuals with a risk of developing arthritis;

"(2) programs to develop improved methods of intervention against those factors which cause individuals to have a high risk of developing arthritis;

"(3) programs to develop health professions and allied health professions personnel highly skilled in the control of arthritis, including continuing education of such personnel;

"(4) community consultative services to facilitate new and problem patient referral from local hospitals and physicians to Arthritis Consultation Boards of the centers for diagnostic workup, including laboratory analyses, and consultations with primary physicians on preferred rehabilitation management; and

"(5) programs to disseminate the results of research and to develop means of standardizing patient data and recordkeeping.

"(c) The programs supported under this section may also carry out projects and programs funded under other provisions of law related to the programs and projects authorized under this section.

"(d) In addition to sums appropriated pursuant to section 301 and other sums appropriated for research on arthritis pursuant to title IV, part D, there is authorized to be

appropriated to carry out this section $5,000,000 for the fiscal year ending June 30, 1975, $10,000,000 for the fiscal year ending June 30, 1976, and $15,000,000 for the fiscal year ending June 30, 1977.

"NATIONAL ARTHRITIS RESEARCH AND DEMONSTRATION CENTERS

"SEC. 438. (a) The Director of the Institute, under policies established by the Director of the National Institutes of Health, and after consultation with the National Advisory Council and consistent with the Arthritis Plan, will provide for the development of centers for basic and clinical research into, training in, and demonstration of, advanced diagnostic, prevention, control, and treatment methods for arthritis, including research into implantable biomaterials and orthopedic procedures; and may enter into cooperative agreements with public or nonprofit private agencies or institutions to pay all or part of the cost of planning, establishing or strengthening, and providing basic operating support for, existing or new such centers.

"(b) The centers developed under this section shall, in addition to carrying out research, training, and demonstration projects, carry out screening, detection, prevention, and control programs, as described under subsection (b) of section 437. Funds paid to centers under this section may be used for—

"(1) staffing and other basic operating costs, including such patient care costs as are required for research;

"(2) training, including training for allied health professions personnel;

"(3) demonstration purposes; and

"(4) the extension, alteration, remodeling, improvement, or repair of buildings and structures (including the provision of equipment) to the extent necessary to make them suitable for use as research and demonstration centers.

Support of a center under this subsection may be for a period of not to exceed three years and may be extended by the Director of the Institute, with the approval of the National Advisory Council, for additional periods of up to three years each.

"(c) The centers supported under this section may also carry out projects and programs funded under other provisions of law related to the programs and projects authorized under this section.

"(d) In addition to sums appropriated pursuant to section 301 and other sums appropriated for research on arthritis pursuant to title IV, part D, there is authorized to be appropriated to carry out this section $10,000,000 for the fiscal year ending June 30, 1975, $15,000,000 for the fiscal

year ending June 30, 1976, and $20,000,000 for the fiscal year ending June 30, 1977.

"ANNUAL REPORTS

"SEC. 439. The Director of the Institute shall, as soon as practicable, but not later than sixty days after the end of each calendar year, prepare, in consultation with the National Advisory Council, and submit to the President and to the Congress a report. Such report shall include (1) a proposal for the Institute's activities under the Arthritis Plan under this part and other provisions of law during the next five years, with an estimate for such additional staff positions and appropriations (including increased appropriations authorizations) as may be required to pursue such activities, and (2) a program evaluation section wherein the activities and accomplishments of the Institute during the preceding calendar year shall be measured against the Director's proposal for that year for activities under the Arthritis Plan.".

[H.R. 14181, introduced by Mr. Rogers (for himself and Mr. Carter) on April 10, 1974;
H.R. 14557, introduced by Mr. Lujan on May 2, 1974;
H.R. 14591, introduced by Mr. Froehlich on May 6, 1974;
H.R. 14598, introduced by Mr. Rogers (for himself, Mr. Carter, Mr. Hastings, Mr. Fascell, Mr. Haley, Mr. Lehman, Mr. Pepper, Mr. Bevill, Mr. Burgener, Mr. Carney of Ohio, Ms. Chisholm, Mr. Corman, Mr. Eilberg, Mr. Froehlich, Mr. Hansen of Idaho, Mr. Hawkins, Mr. Hechler of West Virginia, Mr. Howard, Mr. Luken, Ms. Mink, Mr. Murphy of New York, Mr. Rees, Mr. Rodino, Mr. Roybal, and Ms. Schroeder) on May 6, 1974;
H.R. 14670, introduced by Mr. Carter (for himself, Mrs. Rogers, Mrs. Burke of California, Mr. Brown of California, Mr. Cohen, Mr. du Pont, Mr. Esch, Mr. Hanna, Mr. Harrington, Mr. Hicks, Ms. Holtzman, Mr. Horton, Mr. Hudnut, Mr. Jones of North Carolina, Mr. Mazzoli, Mr. Melcher, Mr. Nix, Mr. Podell, Mr. Preyer, Mr. Roncalio of Wyoming, Mr. Stark, Mr. Symington, Mr. Vander Veen, Mr. Winn, and Mr. Yatron) on May 8, 1974;
H.R. 14756, introduced by Mr. Brotzman on May 14, 1974;
H.R. 14926, introduced by Mr. Rogers (for himself, Mr. Carter, Mr. Kyros, Mr. Jarman, Ms. Abzug, Mr. Biaggi, Mr. Bingham, Mr. Cleveland, Mr. Conte, Mr. Cronin, Mr. Danielson, Mr. Gilman, Mrs. Grasso, Mr. Helstoski, Mr. Matsunaga, Mr. Mosher, Mr. Murtha, Mr. Reid, Mr. Rose, Mr. Rosenthal, Mr. Owens, Mr. Sarbanes, Mr. St Germain, Mr. Studds, and Mr. Won Pat) on May 21, 1974;
H.R. 14934, introduced by Mr. Tiernan on May 21, 1974;
H.R. 15043, introduced by Mr. Hanley on May 29, 1974;
H.R. 14087, introduced by Mr. Brinkley on May 30, 1974;
H.R. 15113, introduced by Mr. Shriver on May 30, 1974;
H.R. 15272, introduced by Mr. Flood on June 6, 1974;
H.R. 15731, introduced by Mr. Carter (for himself, Mr. Rogers, Mr. Coughlin, Mr. Davis of Georgia, Mr. Fulton, Mr. Ginn, Mr. Gunter, Mr. Hanley, Mr. McCloskey, Mr. McEwen, Mr. Moakley, Mr. Roe, Mr. Skubitz, Mr. Stokes, Mr. Whalen, and Mr. Wolff) on July 1, 1974;
H.R. 16042, introduced by Mr. Bob Wilson on July 22, 1974;
H.R. 16122, introduced by Mr. Murphy of Illinois (for himself, Mr. Rogers, Mr. Carter, Mr. Annunzio, Mrs. Collins of Illinois, Mr. Hanrahan, Mr. Madigan, Mr. Metcalfe, Mr. Kluczynski, Mr. Rostenkowski, Mr. Yates, Mr. Roy, Mr. Waldie, and Mr. Anderson of California) on July 25, 1974;
H.R. 16255, introduced by Mr. Green of Pennsylvania on August 5, 1974;
H.R. 16308, introduced by Mr. Murphy of Illinois (for himself, Mr. Rogers, Mr. Carter, Mr. Annunzio, Mrs. Collins of Illinois, Mr. Hanrahan, Mr. Madigan, Mr. Metcalfe, Mr. Kluczynski, Mr. Rostenkowski, Mr. Yates, and Mr. Young of Illinois) on August 7, 1974;
H.R. 16428, introduced by Mr. Wyman on August 14, 1974;
H.R. 16598, introduced by Mr. Edwards of Alabama on September 11, 1974;
H.R. 16620, introduced by Mr. Miller on September 11, 1974;
H.R. 16672, introduced by Mr. Vander Jagt on September 16, 1974;
H.R. 16841, introduced by Mr. Quie on September 24, 1974;
H.R. 17004, introduced by Mr. Johnson of Pennsylvania on October 2, 1974; and
H.R. 17451, introduced by Mr. Aspin on November 19, 1974,

are identical as follows:]

A BILL

To provide for the development of a long range plan to advance the national attack on arthritis and related musculoskeletal diseases and for arthritis training and demonstration centers, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

SECTION 1. This Act may be cited as the "Arthritis Prevention, Treatment, and Rehabilitation Act of 1974".

FINDING AND DECLARATION OF PURPOSE

SEC. 2. (a) The Congress make the following findings—

(1) Arthritis and related musculoskeletal diseases constitute major health problems in the United States

which directly affect more than twenty million Americans of all ages at a cost in medical expenses of approximately $2,500,000,000 a year.

(2) The complications of arthritis lead to many other serious health problems and other severe physical impairments in persons of all ages.

(3) The citizens of the United States should have a full understanding of arthritis and related musculoskeletal diseases and should be encouraged to seek early diagnosis and treatment to prevent or mitigate physical disability.

(4) The attainment of advanced methods of diagnosis and treatment of arthritis and quality trained health professionals in arthritis deserve the highest national priority.

(5) There is a critical shortage of medical facilities and properly trained health professionals and allied health professionals in the United States for arthritis research, prevention, treatment, care, and rehabilitation programs.

(b) It is the purpose of this Act to establish—

(1) a long-range plan—

(A) to expand and coordinate the national research, treatment, and control effort against arthritis and related musculoskeletal diseases;

(B) to advance educational activities for patients, professional and allied health personnel, and the public which will alert the citizens of the United States to the early indications of arthritis and related musculoskeletal diseases; and

(C) to emphasize the significance of early detection and proper control of these diseases and of the complications which may evolve from them;

(2) centers for arthritis prevention, research, screening, early detection, training, treatment, and rehabilitation programs; and

(3) programs to develop new and improved methods of arthritis screening and early detection and to establish a central arthritis screening and early detection data bank.

ARTHRITIS PLAN

SEC. 3. (a) The Director of the National Institutes of Health, with the advice of the advisory council to the Director, shall, within sixty days of the date of the enactment of this section, establish a National Commission on Arthritis and Related Musculoskeletal Diseases (hereinafter in this section referred to as the "Commission").

(b) The Commission shall be composed of seventeen members as follows:

(1) Six members appointed by the Secretary of

Health, Education, and Welfare from scientists or physicians who are not in the employment of the Federal Government, who represent the various specialties and disciplines involving arthritis and related musculoskeletal diseases, and of whom at least two are practicing clinical rheumatologists and at least one is an orthopaedic surgeon.

(2) Four members appointed by the Secretary of Health, Education, and Welfare from the general public. At least two of the members appointed under this paragraph shall be arthritis sufferers.

(3) One member of the National Arthritis, Metabolism, and Digestive Disease Advisory Council whose primary interest is in the field of rheumatology.

(4) The Director of the National Institutes of Health or his designee; the Director of the National Institute of Arthritis, Metabolism, and Digestive Diseases or his designee; the Associate Director for Arthritis and Related Musculoskeletal Diseases of such Institute; the Chief Medical Director of the Veterans' Administration or his designee.

(5) The Directors, or their designees, of the National Institute of Allergy and Infectious Diseases and the National Institute of General Medical Science.

The members of the Commission shall select a chairman from among their own number.

(c) The Commission may appoint an executive director and such additional personnel as it determines are necessary for the performance of the Commission's functions.

(d) Members of the Commission who are officers or employees of the Federal Government shall serve as members of the Commission without compensation in addition to that received in their regular public employment. Members of the Commission who are not officers or employees of the Federal Government shall each receive the daily equivalent of the rate in effect for grade GS–18 of the General Schedule for each day (including traveltime) they are engaged in the performance of their duties as members of the Commission. All members of the Commission shall be entitled to reimbursement for travel, subsistence, and other necessary expenses incurred by them in the performance of their duties as members of the Commission.

(e) The Commission shall survey all Federal, State, and local health programs and activities relating to arthritis and related musculoskeletal diseases and assess the adequacy, technical soundness, and coordination of such programs and activities. All Federal departments and agencies administering health programs and activities relating to arthritis and

related musculoskeletal diseases shall provide such cooperation and assistance relating to such programs and activities as is reasonably necessary for the Commission to make such survey and assessment.

(f) The Commission shall formulate a long-range plan to combat arthritis and related musculoskeletal diseases with specific recommendations for the utilization and organization of national resources for that purpose. Such a plan shall be based on a comprehensive survey investigating the magnitude of arthritis and related musculoskeletal diseases, their epidemiology, their economic and social consequences, and an evaluation of available scientific information and the national resources capable of dealing with the problem. The plan shall include at least the following—

(1) A plan for a coordinated research program encompassing programs of the National Institute of Arthritis, Metabolism, and Digestive Diseases, the National Institute of Allergy and Infectious Diseases, the National Eye Institute, the National Institute of Neurological Diseases and Stroke, the National Heart and Lung Institute, the National Institute of General Medical Sciences, the National Institute of Child Health and Human Development, and the National Cancer Institute, and other Federal and non-Federal programs. This coordinated research program shall provide for—

(A) investigation into the epidemiology, etiology, and prevention and control of arthritis and related musculoskeletal diseases, including investigation into the social, environmental, behaviorial, nutritional, biological, and genetic determinants and influences involved in the epidemiology, etiology, prevention, and control of these diseases;

(B) studies and research into the basic biological processes and mechanisms involved in the underlying normal and abnormal phenomena associated with arthritis, including abnormalities of the immune, musculoskeletal, cardiovascular, and nervous systems, the skin, the gastrointestinal tract, the kidneys, the lungs, and the eyes;

(C) research into the development, trial, and evaluation of techniques, including orthopedic and other surgical procedures and drugs, used in, and approaches to, the diagnosis, early detection, treatment, prevention, and control of arthritis and related musculoskeletal diseases;

(D) establishment of programs that will focus and apply scientific and technological methodologies and processes involving biological, physical, and engineering science to deal with all facets of arthritis, and related musculoskeletal diseases;

(E) establishment of programs for the conduct and direction of field studies, large-scale testing, evaluation, and demonstration of preventive, diagnostic, therapeutic, rehabilitative, and control approaches to arthritis and related musculoskeletal diseases, including studies of the effectiveness of home care programs, the use of mobile care units, community rehabilitation facilities, and other appropriate community public health and social services;

(F) programs to evaluate the current resources for the rehabilitation of the arthritis patient and establish criteria for the potential for rehabilitation of the patient;

(G) programs to investigate alternative screening possibilities to define more adequately the arthritis population and to detect early cases of rehabilitative arthritis and related musculoskeletal diseases;

(H) programs to establish standards of measurement of the severity and rehabilitative responsiveness of disabilities resulting from arthritis and related musculoskeletal diseases;

(I) the development of a common descriptive vocabulary in basic and clinical research and a standardized clinical patient data-card for arthritis and related musculoskeletal diseases for the purpose

of standardizing collection, storage, and retrieval of research and treatment data to facilitate collaborative and comparative studies of large patient populations;

(J) a system for the collection, analysis, and dissemination of all data useful in the screening, prevention, diagnosis, and treatment of arthritis and related musculoskeletal diseases, including the establishment of a national data storage bank on arthritis research, screening, diagnosis, prevention, control, and treatment to collect, catalog, store, and disseminate information as to the practical application of research and other activities pertaining to arthritis and related musculoskeletal diseases;

(K) a program for the acceleration of national efforts for international cooperation in and exchange of knowledge on all aspects of research, screening, early detection, diagnosis, treatment, prevention, and control of arthritis and related musculoskeletal diseases; and

(L) programs to develop new techniques and curriculums for the education and training (including continuing education and training) of scientists, bioengineers, clinicians, surgeons, including ortho-

paedic surgeons, physicians engaged in the practice of family medicine, and other health and allied health professionals and educators in the fields and specialities requisite to the conduct of programs for the screening, early detection, diagnosis, treatment, prevention, and rehabilitation of individuals suffering from arthritis and related musculoskeletal diseases.

(2) proposed Federal, State, and local programs for—

(A) the education and training of scientists, bioengineers, clinicians, surgeons, including orthopedic surgeons, and other health and allied health professionals and educators in the fields and specialties requisite to the conduct of programs regarding arthritis and related musculoskeletal and other related diseases;

(B) the continuing education of physicians engaged in the practice of family medicine and other health and allied health professionals in the diagnosis, treatment, prevention and rehabilitation of individuals suffering from arthritis, and other related diseases;

(C) public education and counseling relating to the early detection, treatment, prevention, control, and rehabilitation of arthritis and related mus-

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culoskeletal diseases, including the dissemination of information to the general public; and

(D) the screening of and detection of members of the general public for the symptoms of arthritis and related musculoskeletal diseases and referral services for appropriate treatment of those who require it.

(g) The Commission may hold such hearings, take such testimony, and sit at such time and places as the Commission deems advisable to develop the long-range plan required by subsection (f).

(h) (1) The Commission shall prepare for each of the Institutes whose programs are to be encompassed by the plan described in subsection (f) (1) budget estimates for each Institute's part of the coordinated arthritis and related musculoskeletal diseases research program described in that subsection. The budget estimates shall be prepared for the fiscal year ending June 30, 1975 and for each of the next two fiscal years.

(2) Within five days after the Budget is transmitted by the President to the Congress for the fiscal year ending June 30, 1975, and for each of the next two fiscal years, the Secretary shall transmit to the Committees on Appropriations of the House of Representatives and the Senate, the Committee on Labor and Public Welfare of the Senate,

and the Committee on Interstate and Foreign Commerce of the United States House of Representatives an estimate of the amounts requested for each of the Institutes for arthritis and related musculoskeletal diseases research, and a comparison of such amounts with the budget estimates prepared by the Commission under paragraph (1).

(i) (1) The Commission shall publish and transmit directly to the Congress (without prior administrative approval or review by the Office of Management and Budget or any other Federal department or agency or official thereof) a final report within two hundred and ten days after the date funds are first appropriated for the implementation of this section. Such report shall contain the long-range plan required by subsection (f), the budget estimates required by subsection (h), and an estimate of additional staff positions required to carry out in each Institute the programs under such plan.

(2) The Commission shall cease to exist on the thirtieth day following the date of the submission of its final report pursuant to paragraph (1) of this subsection.

(j) The Director of the National Institutes of Health shall provide the Commission with such full-time professional and clerical staff, such information, and the services of such consultants as may be necessary to assist the Commission to carry out effectively its function under this section.

(k) There are authorized to be appropriated to carry out the purposes of this section $1,000,000.

ASSOCIATE DIRECTOR FOR ARTHRITIS AND RELATED MUSCULOSKELETAL DISEASES; RESEARCH AND TRAINING CENTERS; AND ARTHRITIS COORDINATING COMMITTEE

SEC. 4. Part D of title IV of the Public Health Service Act is amended by adding at the end thereof the following new sections:

"ASSOCIATE DIRECTOR FOR ARTHRITIS AND RELATED MUSCULOSKELETAL DISEASES

"SEC. 435. There is established within the National Institute on Arthritis, Metabolism, and Digestive Diseases the position of Associate Director for Arthritis and Related Musculoskeletal Diseases (hereinafter in this part referred to as the 'Associate Director'), who shall report directly to the Director of such Institute and who, under the supervision of the Director of such Institute, shall be responsible for programs regarding arthritis and related musculoskeletal diseases within such Institute.

"ARTHRITIS COORDINATING COMMITTEE

"SEC. 436. In order to better coordinate the total National Institutes of Health research activities relating to arthritis and related musculoskeletal diseases, the Director of the National Institutes of Health shall establish an Inter-Institute Arthritis and Related Diseases Coordinating Com-

mittee. This Committee shall be composed of the Directors (or their designated representatives) of each of the Institutes and divisions involved in arthritis-related research and the Associate Director established pursuant to section 435. The Committee will be chaired by the Director of the National Institutes of Health (or his designated representative). Such Committee shall prepare a report as soon after the end of each fiscal year as possible for the Director of the National Institutes of Health detailing the work of the Committee in coordinating the research activities of the National Institutes of Health relating to arthritis and related musculoskeletal diseases during the preceding year.

"ARTHRITIS RESEARCH AND TRAINING CENTERS

"SEC. 437. (a) The Secretary, through the Assistant Secretary of Health, after consultation with the National Advisory Council established under section 434(a), may provide for the development, establishment, construction, and operation of centers for research in, screening and early detection of, diagnosis of, prevention of, training and education related to, and control, treatment and rehabilitation of arthritis and related musculoskeletal diseases. For purposes of this section the term 'construction' means the alteration, remodeling, improvement, expansion, and repair of existing buildings and initial equipment for such buildings.

"(b) Each center developed, established, constructed, or operated under this section shall—

"(1) utilize the facilities of a single institution, or be formed from a consortium of cooperating institutions meeting such research and training qualifications as may be prescribed by the Secretary; and

"(2) conduct—

"(A) basic research into the cause of, and clinical research in the diagnosis, early detection, prevention, control, rehabilitation, and treatment of, arthritis and related musculoskeletal diseases and complications resulting from such diseases, including research into implantable biomaterials and biomechanical and other orthopaedic procedures and into the development of other new diagnostic and treatment methods;

"(B) training programs for physicians and other health and allied professionals in current methods of diagnosis, screening and early detection, prevention, control, rehabilitation, and treatment of such diseases;

"(C) information and continuing education programs for physicians and other health and allied

health professionals who provide primary care for patients with such diseases; and

"(D) screening, detection, prevention, and control programs to—

"(i) develop new and improved methods of detecting individuals with a risk of developing arthritis or a related musculoskeletal disease;

"(ii) develop new and improved methods of intervention against those factors which cause individuals to have a high risk of developing arthritis or a related musculoskeletal disease;

"(iii) disseminate the results of research and patient screening data and develop means of standardizing patient data and recordkeeping in accordance with such regulations as the Secretary may prescribe;

"(iv) develop community consultative services to facilitate new and problem patient referral from local hospitals and physicians to the centers for diagnostic workup, including laboratory analysis, and consultations with primary physicians on preferred rehabilitation management; and

"(v) educate the general public and persons suffering from arthritis and related musculo-

skeletal diseases, including the dissemination of information on the importance of early detection and recognition of signs and symptoms and of seeking prompt followup treatment, on how to cope with the gradual progression of the diseases, and on the importance of self-discipline, proper home care, and compliance with medical directives.

"(e) The Secretary shall, insofar as practicable, provide for an equitable geographical distribution of centers developed, established, constructed, or operated under this section.

"(d) Operational support of a center under this section may be for a period not to exceed three years.

"(e) The Secretary shall evaluate on an annual basis the activities of centers receiving support under this section and shall report to the Congress (on or before June 30 of each year) the results of his evaluation.

"(f) (1) For the purposes of establishing new research and training centers in institutions which do not have centers conducting research, training, and other activities relating to arthritis and related musculoskeletal diseases, there are authorized to be appropriated $3,000,000 for fiscal year ending June 30, 1975, $4,000,000 for fiscal year ending

June 30, 1976, and $5,000,000 for fiscal year ending June 30, 1977.

"(2) For the establishment of centers (other than centers for which appropriations are authorized by paragraph (1)) and for the development, construction, and operation of centers, there are authorized to be appropriated $18,000,000 for fiscal year ending June 30, 1975, $20,000,000 for fiscal year ending June 30, 1976, and $22,000,000 for fiscal year ending June 30, 1977.

"ARTHRITIS SCREENING, EARLY DETECTION, PREVENTION, AND CONTROL DEMONSTRATION PROGRAMS; DATA BANK

"SEC. 438. (a) The Secretary, through the Assistant Secretary of Health may establish and support projects for the development and demonstration of new or improved methods for the screening and detection, prevention, and control of arthritis and related musculoskeletal diseases. Such projects shall provide for support of and cooperation with other Federal health agencies, State, local, and regional public health agencies, and other public and private nonprofit agencies and institutions.

"(b) Screening, detection, and control projects under this section shall include—

"(1) programs to develop new and improved methods of screening and detection in individuals with a

risk of developing arthritis and related musculoskeletal diseases;

"(2) programs to develop new and improved methods of screening and early detection of individuals with asymptomatic arthritis and related musculoskeletal diseases;

"(3) programs to develop new and improved methods of detection, referral, and early diagnosis of individuals with symptomatic arthritis, and related musculoskeletal diseases;

"(4) programs to develop new and improved methods for patient referral from local hospitals and physicians to appropriate centers for early diagnosis and treatment; and

"(5) programs to develop new and improved means of standardizing patient data and recordkeeping.

"(c) Projects established or supported under this section shall cooperate with the Secretary in coordinating screening and detection programs, in the utilization of standardized patient data and recordkeeping practices and procedures as prescribed by the Secretary, and in the collection, storage, analysis, retrieval, and dissemination of data for the purposes of subsection (c) of this section.

"(d) There are authorized to be appropriated to carry out this section $5,000,000 for fiscal year ending June 30,

1975, $6,000,000 for fiscal year ending June 30, 1976, and $7,000,000 for fiscal year ending June 30, 1977.

"(e) (1) As soon as practicable after the date of enactment of this section the Secretary, through the Assistant Secretary of Health, shall establish the Arthritis Screening and Detection Data Bank for the collection, storage, analysis, retrieval, and dissemination of all data useful in screening, prevention, and early detection involving patient populations with asymptomatic and symptomatic types of arthritis and related musculoskeletal diseases, including, where possible, data involving general populations for the purpose of detection of individuals with a risk of developing arthritis or related musculoskeletal diseases.

"(2) The Secretary shall provide for standardization of patient data and recordkeeping for the collection, storage, analysis, retrieval, and dissemination of such data in cooperation with the centers and programs established or supported under section 437 and this section and with other persons engaged in arthritis and related musculoskeletal disease programs.

"(3) There are authorized to be appropriated such sums as may be necessary to carry out this subsection."

RESEARCH FUNDING; ADVISORY COUNCIL

SEC. 5. (a) Section 431 of the Public Health Service Act is amended by adding at the end thereof the following new subsection:

"(c) Of the sums appropriated for any fiscal year under this Act for the National Institutes of Health, not less than $500,000 shall be obligated for basic and clinical orthopaedic research conducted or supported by the National Institute on Arthritis, Rheumatism, and Metabolic Diseases which relates to the methods of preventing, controlling, and treating arthritis and related musculoskeletal diseases, including research in implantable biomaterials and biomechanical and other orthopaedic procedures and research in the development of new and improved orthopaedic treatment methods."

(b) Section 434 (b) of such Act is amended by adding at the end thereof the following: "The Advisory Council shall review applications made to the Director for grants for research projects related to arthritis and related musculoskeletal diseases and shall recommend to the Director for approval those applications and contracts which the Council determines will best carry out the purposes of this part. The Advisory Council shall also review and evaluate the programs under sections 437 and 438 and shall recommend to the Director such changes in the administration of such programs as it determines are necessary to carry out their purpose."

93D CONGRESS
2D SESSION

S. 2854

IN THE HOUSE OF REPRESENTATIVES

OCTOBER 15, 1974
Referred to the Committee on Interstate and Foreign Commerce

AN ACT

To amend the Public Health Service Act to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "National Arthritis Act".

FINDINGS AND DECLARATION OF PURPOSE

SEC. 2. (a) The Congress hereby finds and declares that—

(1) arthritis and related musculoskeletal and other related diseases represent one of the most serious and widespread health problems in the United States in that they afflict more than twenty million Americans;

(2) arthritis is the greatest single cause of chronic pain and disability;

(3) the complications of arthritis lead to many other serious health problems;

(4) uncontrolled arthritis significantly decreases the quality of life and has a major negative economic, social, and psychological impact on the families of its victims and society generally;

(5) the severity of arthritis in children and most adolescents is greater than in adults and this involves greater problems in the management of the disease;

(6) athletic and other types of joint injuries can lead to arthritis;

(7) the annual cost to the national economy in 1970 due to arthritis, in medical care bills and lost wages, was $9,200,000,000;

(8) the workdays lost due to disability caused by arthritis totaled over 14,500,000 in 1970;

(9) although today's currently available therapy and surgical techniques for improving the functional state of millions of arthritics are significantly more effective than those of a decade ago, they remain stopgap measures which neither prevent nor cure the disease; and therefore the attainment of better methods of diagnosis and treatment of arthritis through research and

through education of health professionals and allied health professionals deserves the highest national priority;

(10) there are inadequate numbers of medical facilities and of properly trained personnel to provide treatment and rehabilitation for persons suffering from arthritis, and inadequate numbers of properly trained personnel to train other health personnel interested in pursuing either a research or clinical career in rheumatology;

(11) the citizens of the United States should have a full understanding of the nature of the human, social, and economic impact of arthritis and should be encouraged to seek early diagnosis and treatment to prevent or lessen disability resulting from arthritis; and

(12) there is great potential for making major advances against arthritis in the National Institute of Arthritis, Metabolism, and Digestive Diseases, in concert with other Institutes of the National Institutes of Health, and public and private organizations capable of necessary research and public education in arthritis.

(b) It is therefore the purpose of this Act to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis.

NATIONAL ARTHRITIS PROGRAM

SEC. 3. Part D of title IV of the Public Health Service Act is amended by adding at the end thereof the following new sections:

"NATIONAL TASK FORCE ON ARTHRITIS

"SEC. 437. (a) The Secretary, within sixty days after the date of enactment of this section, shall establish a National Task Force on Arthritis (hereinafter in this part referred to as the 'Task Force') to formulate a long-range plan (hereinafter in this part referred to as the 'Arthritis Plan') to combat arthritis and related musculoskeletal and other related diseases (hereinafter in this part referred to as 'arthritis'). The Arthritis Plan shall include recommendations for the utilization and organization of national resources for the campaign against arthritis, and a program for the National Institute of Arthritis, Metabolism, and Digestive Diseases (hereinafter in this part referred to as the 'Institute') as a major participant in the campaign against arthritis.

"(b) The Arthritis Plan developed by the Task Force shall provide for—

"(1) programs for investigation into the epidemiology, etiology, and prevention and control of arthritis, including investigation into the social, environmental, behavioral, nutritional, biological, and genetic deter-

minants and influences involved in the epidemiology, etiology, prevention, and control of arthritis;

"(2) studies and research into the basic biological processes and mechanisms involved in the underlying normal and abnormal phenomena associated with arthritis, including but not limited to, abnormalities of the immune, musculoskeletal, cardiovascular, and nervous systems, the skin, the gastrointestinal tract, the kidneys, the lungs, and the eyes;

"(3) research into the development, trial, and evaluation of techniques, including surgical procedures and drugs, used in, and approaches to, the diagnosis, early detection, treatment, prevention, and control of arthritis;

"(4) establishment of programs that will focus and apply scientific and technological methodologies and processes involving biological, physical, and engineering science to deal with all facets of arthritis, including traumatic arthritis;

"(5) establishment of programs for the conduct and direction of field studies, large-scale testing, evaluation, and demonstration of preventive, diagnostic, therapeutic, rehabilitative, and control approaches to arthritis, including studies of the effectiveness of home-care programs, the use of mobile care units, community

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rehabilitation facilities, and other appropriate community public health and social services;

"(6) studies of the feasibility and possible benefits accruing from team training of health and allied health professionals in the treatment and rehabilitation of individuals suffering from arthritis;

"(7) programs to evaluate the current resources for the rehabilitation of the arthritis patient and establish criteria for the potential for rehabilitation of the patient;

"(8) programs to investigate alternative screening possibilities to define more adequately the arthritis population and to detect early cases of rehabilitative arthritis;

"(9) programs for the education and training of scientists, bioengineers, primary care physicians, clinicians, surgeons, including orthopedic surgeons, and other health and allied health professionals and educators in the fields and specialties requisite to the conduct of programs regarding arthritis;

"(10) programs for the continuing education of health and allied health professionals in the diagnosis, treatment, and rehabilitation of individuals suffering from arthritis;

"(11) programs for public education relating to all

aspects of arthritis, including periodic public information programs on the most current developments in diagnostic and treatment procedures with a view to discouraging the promotion and utilization of unapproved and ineffective diagnostic, prevention, treatment, and control methods and unapproved and ineffective therapeutic drugs and devices;

"(12) programs to establish standards of measurement of the severity and rehabilitative responsiveness of disabilities resulting from arthritis;

"(13) the development of a common descriptive vocabulary in basic and clinical research in arthritis for the purpose of standardizing collection, storage, and retrieval of research and treatment data to facilitate collaborative and comparative studies of large patient populations;

"(14) the development of a national data storage bank on arthritis research, diagnosis, prevention, control and treatment, to collect and make available information as to the practical application of research and other activities pursuant to this part; and

"(15) a plan for international cooperation in and exchange of knowledge on all aspects of research, diagnosis, treatment, prevention, and control of arthritis.

"(c) The Task Force shall be composed of seventeen

members who are eminently qualified to serve on such Task Force, as follows:

"(1) the Secretary or his designee, the Director of the National Institutes of Health or his designee, the Associate Director for Arthritis of the Institute (as established by section 438), the Director of the National Institute of General Medical Sciences or his designee, the Chief Medical Director of the Veterans Administration, and the Secretary of Defense or his designee, who shall serve as ex officio members;

"(2) seven members who shall be scientists or physicians representing the various specialties and disciplines pertinent to arthritis, of whom at least two are practicing clinical rheumatologists and one is an orthopedic surgeon;

"(3) three members from the general public, of whom at least two are arthritis sufferers; and

"(4) one member of the National Arthritis, Metabolism, and Digestive Diseases Advisory Council (hereinafter referred to as the National Advisory Council) whose primary interest is in the field of rheumatology.

"(d) The Secretary shall designate one member of the Task Force as Chairman of the Task Force. The Task Force shall first meet at the call of the Secretary, and there-

after at the call of the Chairman of the Task Force, and shall meet not less than three times.

"(e) (1) The Task Force shall publish and transmit to the Director of the Institute the Arthritis Plan not later than nine months after the date of enactment of this section.

"(2) No later than sixty days after the Task Force transmits the Arthritis Plan to the Director of the Institute, the Director shall submit to Congress the Arthritis Plan, his proposals for Institute activities under this part for the first five years under the Arthritis Plan, and an estimate of such additional staff positions and appropriations (including increased appropriations authorizations) as may be required to carry out such activities. If the plan and subsequent reports to be submitted pursuant to subsection (e) (1) and (2) of this section are submitted, prior to submission to the Congress, for review by the Office of Management and Budget or any other Federal department or agency or official thereof, (1) the plan or report submitted to the Congress shall specify the changes and the reasons therefor made during any such review process, and (2) if any such review process delays the submission of such plan or report to the Congress beyond the date established for such submission by this section, the Director shall immediately on such date submit to the Congress the plan or report in exactly the form it was submitted to such review process.

"(f) The Task Force may hold such hearings, take such testimony, and sit and act at such times and places as the Task Force deems advisable to develop the Arthritis Plan.

"(g) The Director of the Institute shall—

"(1) designate a member of the staff of such Institute to act as Executive Secretary of the Task Force; and

"(2) provide the Task Force with such full-time professional and clerical staff, such information, and the services of such consultants as may be necessary to assist the Task Force to carry out effectively its functions under this section.

"(h) Members of the Task Force who are not officers or employees of the United States shall receive for each day they are engaged in the performance of the functions of the Task Force compensation at rates not to exceed the daily equivalent of the annual rate in effect for grade GS–18 of the General Schedule, including traveltime; and all members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by section 5703, title 5, United States Code, for persons in the Government service employed intermittently.

"(i) In addition to sums appropriated pursuant to

section 301 and other sums appropriated for research on arthritis pursuant to title IV, part D, there is authorized to be appropriated $500,000 for the fiscal years ending June 30, 1975, and June 30, 1976, to carry out the purposes of this section, and such sums shall remain available until expended.

"ASSOCIATE DIRECTOR FOR ARTHRITIS AND ESTABLISHMENT OF COMMITTEES

"SEC. 438. (a) There is established within the Institute the position of Associate Director for Arthritis (hereinafter in this part referred to as the 'Associate Director'), who shall report directly to the Director of such Institute and who, under the supervision of the Director of such Institute, shall be responsible for programs regarding arthritis within such Institute.

"(b) In order to improve coordination of the total National Institutes of Health research activities relating to arthritis, the Director of the National Institutes of Health shall establish an Inter-Institute Arthritis Coordinating Committee to be composed of representatives who can make policy commitments for each of the Institutes and divisions involved in arthritis-related research. The committee will be chaired by the Associate Director and will prepare a report as soon (but not later than sixty days) after the end of each fiscal year as possible for the Director of the National Institutes of Health detailing the work of the committee in

coordinating the research activities of the National Institutes of Health relating to arthritis during the preceeding year.

"(c) In order to improve coordination of all activities in the Department of Health, Education, and Welfare relating to arthritis, the Secretary shall establish an Intradepartmental Arthritis Coordinating Committee to be composed of representatives who can make policy commitments for each of the administrations, agencies, and divisions within the Department involved in research (including approval of drugs and devices), health services, or rehabilitation programs affecting arthritis. The committee will be chaired by the Associate Director and will prepare a report, as soon (but not later than sixty days) after the end of each fiscal year as possible, for the Secretary detailing the work of the committee in seeking to improve coordination of departmental activities relating to arthritis during the preceding fiscal year.

"(d) (1) There is established within the Federal Government an Interagency Technical Committee on Arthritis which shall be responsible for promoting the coordination of those aspects of all Federal health programs and activities relating to arthritis to assure the adequacy and technical soundness of such programs and activities and to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities.

"(2) The Director and Associate Director for Arthritis of the Institute shall serve as chairman and co-chairman respectively, of such Committee, and such Committee shall include representation from the Veterans Administration, the Department of Defense, and all other Federal departments and agencies administering programs involving health functions or responsibilities as determined by the Secretary.

"(3) The Committee shall meet at the call of the chairman, but not less often than four times a year.

"ARTHRITIS SCREENING, EARLY DETECTION, PREVENTION, AND CONTROL PROGRAMS

"SEC. 439A. (a) The Director of the Institute, under policies established by the Director of the National Institutes of Health, and after consultation with the National Advisory Council and consistent with the Arthritis Plan, shall establish programs as necessary for cooperation with other Federal health agencies, State, local, and regional public health agencies, and nonprofit private health agencies, in the screening, detection, prevention, and control of arthritis which emphasize the development of new methods, and the dissemination of the knowledge about these methods to the health professions.

"(b) Screening, detection, prevention, and control programs under this part shall include—

"(1) programs to develop improved methods of detecting individuals with a risk of developing arthritis;

"(2) programs to develop improved methods of intervention against those factors which cause individuals to have a high risk of developing arthritis;

"(3) programs to develop health professions and allied health professions personnel highly skilled in the control of arthritis, including continuing education of such personnel;

"(4) community consultative services to facilitate new and problem patient referral from local hospitals and physicians to Arthritis Consultation Boards of the centers for diagnostic workup, including laboratory analyses, and consultations with primary physicians on preferred rehabilitation management;

"(5) programs to disseminate the results of research and to develop means of standardizing patient data and recordkeeping; and

"(6) programs (A) to educate the general public and persons suffering from arthritis, which shall include the dissemination of information on the importance of early detection and recognition of signs and symptoms and of seeking prompt followup treatment, on the importance of self-discipline and on compliance with medical directives, and (B) to discourage the promotion and

utilization of unapproved and ineffective diagnostic, prevention, treatment, and control methods and unapproved and ineffective therapeutic drugs and devices.

"(c) The programs supported under this section may also carry out projects and programs funded under bther provisions of law related to the programs and projects authorized under this section.

"(d) In addition to sums appropriated pursuant to section 301 and other sums appropriated for researeh on arthritis pursuant to title IV, part D, there are authorized to be appropriated to carry out this section $5,000,000 for the fiscal year ending June 30, 1975, $10,000,000 for the fiscal year ending June 30, 1976, and $15,000,000 for the fiscal year ending June 30, 1977.

"(e) (1) As soon as praeticable after the date of enactment of this section, the Director of the Institute shall establish the Arthritis Screening and Detection Data Bank for the collection, storage, analysis, retrieval, and dissemination of all data useful in sereening, prevention, control, and early detection for patient populations with asymptomatie and symptomatic types of arthritis, including, where possible, data involving general populations collected for the purpose of detection of individuals with a risk of developing arthritis.

"(2) The Secretary shall provide for standardization of patient data and recordkeeping for the collection, storage,

analysis, retrieval, and dissemination of such data in cooperation with the centers and programs established or supported under section 439B and this section and with other persons engaged in arthritis programs.

"NATIONAL ARTHRITIS RESEARCH AND DEMONSTRATION CENTERS

"SEC. 439B. (a) The Director of the Institute under policies established by the Director of the National Institutes of Health, and after consultation with the National Advisory Council and consistent with the Arthritis Plan, will provide for the development of centers for basic and clinical research into, training in, and demonstration of, advanced diagnostic, prevention, control, and treatment methods for arthritis, including research into implantable biomaterials and orthopedic procedures; and may enter into cooperative agreements with public or nonprofit private agencies or institutions to pay all or part of the cost of planning, establishing or strengthening, and providing basic operating support for, existing or new such centers.

"(b) The centers developed under this section shall, in addition to carrying out research, training, and demonstration projects, carry out screening, detection, treatment, prevention, and control programs, as described under subsection (b) of section 439A. Funds paid to centers under this section may be used for—

"(1) staffing and other basic operating costs, including such patient care costs as are required for research;

"(2) training, including training for allied health professions personnel;

"(3) demonstration purposes; and

"(4) the extension, alteration, remodeling, improvement, or repair of buildings and structures (including the provision of equipment) to the extent necessary to make them suitable for use as research and demonstration centers.

Support of a center under this subsection may be for a period of not to exceed three years and may be extended by the Director of the Institute, with the approval of the National Advisory Council, for additional periods of up to three years each.

"(c) The centers supported under this section may also carry out projects and programs funded under other provisions of law related to the programs and projects authorized under this section.

"(d) The Director of the Institute shall, insofar as practicable, provide for an equitable geographical distribution of centers developed under this section with appropriate attention to the need for centers having the capability of conducting research, training, treatment, and rehabilitation

programs especially suited to meeting the needs of children affected by arthritis.

"(e) In addition to sums appropriated pursuant to section 301 and other sums appropriated for research on arthritis pursuant to title IV, part D, there is authorized to be appropriated to carry out this section $10,000,000 for the fiscal year ending June 30, 1975, $15,000,000 for the fiscal year ending June 30, 1976, and $20,000,000 for the fiscal year ending June 30, 1977.

"ANNUAL REPORTS

"SEC. 439C. The Director of the Institute shall, as soon as practicable, but not later than sixty days, after the end of each calendar year, prepare, in consultation with the National Advisory Council, and submit to the President and to the Congress a report. Such report shall include (1) a proposal for the Institute's activities under the Arthritis Plan under this part and other provisions of law during the next five years, with an estimate for such additional staff positions and appropriations (including increased appropriations authorizations) as may be required to pursue such activities, and (2) a program evaluation section, wherein the activities and accomplishments of the Institute during the pre-

ceding calendar year shall be measured against the Director's proposal for that year for activities under the Arthritis Plan.".

Passed the Senate October 11, 1974.

Attest: FRANCIS R. VALEO,

Secretary.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
Washington, D.C., July 8, 1974.

Hon. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce, House of Representatives, Washington, D.C.

DEAR MR. CHAIRMAN: This is in response to your request of January 21, 1974, for a report on H.R. 12150, a bill "To amend the Public Health Service Act so as to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis."

The bill would require the Secretary of Health, Education, and Welfare to establish a National Task Force on Arthritis to formulate a long-range plan to combat arthritis and related musculoskeletal and other related diseases. This task force would be composed of 16 qualified members as follows: The Secretary or his designee, the Associate Director of Arthritis of the National Institute of Arthritis, Metabolism, and Digestive Diseases, the Chief Medical Director of the Veterans Administration, and the Secretary of Defense or his designee; seven scientists and physicians representing the various specialities and disciplines relevant to arthritis, including two practicing rheumatologists; three members from the general public including at least two patients with arthritis; and one member of the National Arthritis, Metabolism, and Digestive Diseases Advisory Council.

The Arthritis Plan developed by the Task Force shall provide for broad programs of research related to numerous facets of arthritis, encompassing fundamental studies, social, environmental and epidemiological investigations, clinical studies, and therapeutic trials and investigations of how to provide optimal service to arthritis patients on a community level. In addition, there would be provision for programs for the education and training of relevant professionals, for continuing education of health and allied health professionals, and for the development of a national data storage bank on arthritis.

The bill would also establish the position of Associate Director for Arthritis within the National Institute of Arthritis, Metabolism, and Digestive Diseases, an Inter-Institute Arthritis Coordinating Committee within the National Institutes of Health, and an Interagency Technical Committee on Arthritis within the Federal Government.

The bill would also authorize the establishment of arthritis screening, early detection, prevention, and control programs, with authorizations of $5, $10, and $15 million for fiscal years 1975–1977, respectively, and National Arthritis Research and Demonstration Centers, with additional authorizations of $10, $15, and $20 million for fiscal years 1975–1977, respectively. In addition, the Director of the National Institute of Arthritis, Metabolism, and Digestive Diseases shall submit an annual report to the President and to the Congress which includes a five-year plan and an evaluation of the program.

The Department is in agreement that arthritis and related musculoskeletal diseases represent a serious and widespread health problem in the United States, and that attainment of better methods of treatment of this disease deserves high priority. To that effect, the Department is supporting a well-financed research attack on arthritis and related musculoskeletal and connective tissue diseases through the National Institutes of Health. The lead Institute in this effort is the National Institute of Arthritis, Metabolism, and Digestive Diseases, with a budget for arthritis and related research of $13.94 million in fiscal year 1974 and a request of $13.86 million for fiscal year 1975.

We have been advised by knowledgeable experts on arthritis that at present the research advance against this serious disorder is slowed down primarily by the difficult nature of the subject matter under study. Future breakthroughs in our knowledge of arthritis may well have to depend on multiple general advances on a broad front of our biomedical knowledge ranging from the most fundamental aspects of tissue biology on a cellular level and basic immunology through applied clinical advances in orthopedic surgery.

Given the present state of knowledge, the effectiveness of a formalized long-range plan of how to combat this serious health problem is doubtful and would itself be dependent on new research ideas and advances. Without these, and since outright prevention of the disease is impossible at the present state of our knowledge, most plans would have to address themselves primarily to socio-economic aspects of bringing the best currently available treatment to the greatest number of patients afflicted with the disease.

Adequate legislative authority already exists for the creation of the position of Associate Director for Arthritis within the National Institute of Arthritis, Metabolism, and Digestive Diseases, and we therefore see no need to establish it statutorily. Moreover, as a general rule, we are opposed to the creation of positions by statute because it reduces the Secretary's flexibility to manage effectively in the face of changing priority.

With respect to the proposed arthritis control programs and research and demonstration centers, again no special legislative authority is required. Likewise, the creation of an Inter-Institute Arthritis Coordinating Committee within the National Institutes of Health and an Interagency Technical Commitee on Arthritis within the Federal Government requires no special legislative authorization. Moreover, we see no need for the creation of these committees because there are already numerous effective informal communications among the NIH Institutes on this subject as well as with other Federal Departments, including those specified in H.R. 12150.

Although the intended objectives of H.R. 12150 are shared by the Department, we believe existing statutory authority is adequate for an effective Federal support of arthritis programs and that no new legislation is required. It is our feeling that through the National Institute of Arthritis, Metabolism, and Digestive Diseases the Government already possesses the essential capabilities to carry out the programs specified in H.R. 12150.

For these and other reasons enumerated above, we recommend that H.R. 12150 not be enacted into law.

We are advised by the Office of Management and Budget that there is no objection to the presentation of this report from the standpoint of the Administration's program.

Sincerely,

CASPAR W. WEINBERGER, *Secretary.*

EXECUTIVE OFFICE OF THE PRESIDENT,
OFFICE OF MANAGEMENT AND BUDGET,
Washington, D.C., July 8, 1974.

Hon. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce, House of Representatives, Washington, D.C.

DEAR MR. CHAIRMAN: This is in response to your request of January 21, 1974 for the views of this Office on H.R. 12150, a bill "To amend the Public Health Service Act so as to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases in order to advance a national attack on arthritis."

In its report to your Committee, the Department of Health, Education, and Welfare states its reasons for recommending against enactment of H.R. 12150. HEW believes existing statutory authority is adequate for an effective Federal support of arthritis programs and that no new legislation is required. Furthermore, HEW states that through the National Institute of Arthritis, Metabolism, and Digestive Diseases the Federal Government already possesses the essential capabilities to carry out the programs specified in H.R. 12150.

We concur with the views expressed by the Department in its report. Accordingly, we recommend against enactment of H.R. 12150.

Sincerely,

WILFRED H. ROMMEL,
Assistant Director for Legislative Reference.

Mr. ROGERS. Dr. Carter, I believe you have a statement.

Mr. CARTER. Thank you, Mr. Chairman. I think you have taken care of the major portion of it. However, I am very much interested in this particular disease and, in the past, I have had many patients who were crippled by arthritis. I remember in an orthopedics book which I studied, on page 147, a picture of a child with Still's disease, rheumatoid arthritis of the young.

I believe that little picture there helped me do fairly well in arthritis. It inspired me somewhat in treating people with rheumatoid

arthritis in particular, and in most cases it is an extremely depressing experience because there is no known cause and there is no cure, except in recent years there has been some help by Dr. Brown, formerly of George Washington University here in the city. I believe he is still perhaps professor emeritus there. For 20-odd years he has done research in the subject of rheumatoid arthritis, and I feel some of his treatments have particularly benefited youngsters with rheumatoid arthritis. In fact, one that I knew personally was evidently cured, since the youngster, after treatment, is now a grown young man and healthy in all aspects.

I believe, too, that this disease affects so many people in our country that we should focus upon it in appropriating or authorizing funds for the disease. I believe it is wise for us to make some authorizations and subsequent appropriations in the area of morbidity, mortality, and economic impact. If there is any disease which has a greater morbidity and economic impact than rheumatoid arthritis or arthritis per se, then I don't know what it is.

We have worked out this legislation; I believe parts of the bill need amending, but I think it is good legislation and, for my part, I am going to do everything I can for its passage.

I would hope that the administration will look with favor upon this legislation since it costs less than a destroyer and would have a helpful effect upon our people rather than a destructive effect. Notwithstanding, I certainly believe in an adequate defense for this great country of ours, but I believe our priorities may well be misdirected when we continue to build to destroy rather than to cure or get at the cause of illnesses and relieve people who have this difficulty.

And I would hope that our good friends who testify today would let what they have to say be tempered with mercy and hope for those who suffer from this very tragic disease. Thank you, Mr. Chairman.

Mr. ROGERS. Thank you, Dr. Carter. Mr. Preyer.

Mr. PREYER. I have no comment at this time.

Mr. ROGERS. Without objection, the Chair wishes to place in the record, as though read, statements submitted by Congressmen Spark M. Matsunaga of Hawaii, James C. Cleveland of New Hampshire, and Clarence E. Miller of Ohio.

STATEMENT OF HON. SPARK M. MATSUNAGA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF HAWAII

Mr. MATSUNAGA. Mr. Chairman, thank you for giving me this opportunity to express my support for H.R. 14181, which would establish a long range attack on arthritis. As you know, I am a sponsor of identical legislation.

Arthritis poses a serious national problem. Both its human costs and its economic costs are great.

Over 50 million Americans suffer the pain of arthritis, 20 million to an extent that requires medical attention. Arthritis strikes people of all ages, and it is the No. 1 crippler of Americans.

Americans spend an estimated $2.5 billion per year on medical bills and an additional $1 billion a year for medications to provide relief from the symptoms of arthritis. The bill for lost work time charged

to arthritis is $3.5 billion a year. These and other costs raise the estimated total arthritis expense to Americans to over $9 billion each year.

Little is known about this disease; there is no known cure nor any effective prevention.

The arthritis centers which H.R. 14181 will establish will permit the balanced clinical and research approach needed to advance our knowledge about this disease, and to develop preventive measures to stop its onset and inhibit its progress.

These arthritis centers will integrate expanded rheumatology units with orthopaedic units specializing in arthritis surgery in university-affiliated hospitals. This will combine the various medical disciplines involved in the investigation of arthritis together as a team to allow the translation of the results of research into new modes of care. Thus, the possibility of major new clinical advances will be substantially increased.

H.R. 14181 will also provide support for medical schools to establish new research and teaching capability in rheumatology to train medical students, interns, and residents about this critical field of medicine.

Finally, this bill also provides a basis for an orthopaedic intramural research program at the Arthritis Institute of the National Institutes of Health. This integration of orthopaedics and rheumatology into the arthritis research already being conducted by the Arthritis Institute will greatly facilitate this research.

Compared to the costs of arthritis, the amounts authorized by this bill are very modest, averaging about $30 million per year over the next 3 years. Yet this will more than double the yearly sum that the Federal Government now devotes to arthritis research. The potential return on this investment is great. One HEW cost-benefit study determined that there is a $40 return for every $1 invested in arthritis research. Of course the return in terms of relief from suffering to those afflicted with the disease cannot conveniently be measured in dollars.

Mr. Chairman, as a sponsor of a bill identical to your own H.R. 14181, I urge that it be approved expeditiously. Thank you for this opportunity to present my views on this meritorious legislation.

Thank you again, Mr. Chairman.

STATEMENT OF HON. JAMES C. CLEVELAND, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW HAMPSHIRE

Mr. CLEVELAND. Mr. Chairman, I welcome this opportunity to present my views on behalf of H.R. 14181, the Arthritis Prevention, Treatment and Rehabilitation Act of 1974. This bill would amend the Public Health Service Act in order to advance the national attack on arthritis and related musculoskeletal diseases.

As a cosponsor of H.R. 14181, it is my hope that through this legislation we will be able to provide for the development of a long-range plan to advance the national attack on arthritis, which is the Nation's No. 1 crippling disease, affecting more than 50 million Americans in some way.

I have long felt that chronic diseases such as arthritis require a balance of basic and clinical, or patient-oriented, research in order to be

able to probe into the root cause of the disease, and, subsequently, to develop preventive measures to stop the onset or inhibit the progress of the disease.

The purpose of the Arthritis Prevention, Treatment and Rehabilitation Act is to enable a selected number of university based rheumatology units to be expanded into "Arthritis Research and Training Centers" in order to substantially increase the possibility of major new research findings in arthritis within the next few years.

I feel that if we detect arthritis at its early stages, and treat it properly, we could prevent years of pain and disability, as well as deformity. I think this is a challenge which should be met and feel this legislation will present the opportunity for the research that is needed.

STATEMENT OF HON. CLARENCE E. MILLER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OHIO

Mr. MILLER. Mr. Chairman, I appreciate this opportunity to offer testimony on the Arthritis Prevention Treatment and Rehabilitation Act legislation and, in particular, my bill, H.R. 16620.

In my home state of Ohio, whose population is over 10 million, there are only two arthritis clinical research centers. Their purpose is to perform research, offer patient care and teach physicians and allied health personnel about the disease. The University of Cincinnati College of Medicine sees an average of only 70 patients at the weekly arthritis clinic while 20 patients per week attend a special clinic for children. Last year, Case Western Reserve University School of Medicine in Cleveland treated 2,750 patients at its two clinics. The accomplishments of these centers are important, but clearly more trained personnel and more arthritis research centers must be made available. Ohio's situation is not unique—across the country, arthritis victims are faced with a shortage of quality trained health professionals and medical facilities.

H.R. 16620 ties in with the Congress' program to provide better health care and health care delivery systems in general to the American people by focussing congressional attention on the seriousness of arthritis and upgrading it in importance in the NIH hierarchy of research initiatives. H.R. 16620 proposes to expand public knowledge about the disease, coordinate and concentrate research, and improve training, care, treatment and rehabilitation programs. The fact is that arthritis will develop in almost every citizen in one form or another. Currently, millions of tax dollars are spent on medical care and welfare payments for arthritis victims already disabled—3,500,000 people are disabled at any one time—while little is being done to prevent disability in the first place.

The infusion of Federal dollars into research and treatment efforts means the hope of relief from pain and suffering for 50 million arthritis victims—20 million of whom have arthritis severely enough to require medical care. I, therefore, urge the committee's favorable support of this legislation.

Mr. ROGERS. Dr. Simmons, before you testify, our distinguished colleague from the other body is here. We are delighted to have Senator Case, and we would be delighted to have you say anything you would like to at this time, Senator. We know of your great interest in this matter.

STATEMENT OF HON. CLIFFORD P. CASE, A U.S. SENATOR FROM THE STATE OF NEW JERSEY

Senator CASE. Thank you, Mr. Chairman and members of the committee. I am here, first of all, because I am very much interested in this bill, which we have dealt with properly, I think, in the Senate, and I am sure that this body will under your able leadership.

But I am here particularly because one of our House colleagues is ill, I am sorry to say, and in the hospital, Jim Howard, who was to have introduced the witness who appears before you today. He couldn't because he is, I understand suffering from exhaustion. We hope he will be in good shape soon.

Cal Boggs of Delaware, a veteran of the wars, political and other wars, Governor, and Member of the House and the Senate and now still active in good works, asked me this morning to stop over because he is interested in having people do nice things and pleasant things and he thought I should have the chance to introduce to this committee Charles Harding, who is chairman of the Arthritis Foundation now, a most able and distinguished man, highly qualified for the important job that he has undertaken over the last 2 years.

I know the committee will be glad in due course to hear him, and I am most grateful to you and to you gentlemen for deferring just a moment so I can get back to work. So I leave you to your happy task this afternoon.

Mr. ROGERS. Thank you very much, Senator. We are delighted to have you here. We particularly welcome Mr. Harding and we will be pleased to receive his testimony shortly. Thank you for your presence here today and your interest.

We do have a vote. Before we begin, I think the committee will recess for 5 minutes to cast our votes and be back.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order, please. Our first witness will be Dr. Henry Simmons, Deputy Assistant Secretary for Health, Department of Health, Education, and Welfare, accompanied by Dr. Whedon, Director of the National Institute of Arthritis, Metabolism, and Digestive Diseases. We welcome you gentlemen and will be pleased to receive your statement.

I think I might say, before we begin, that we are very pleased to see Senator Boggs here, who has been a friend of all the members of the subcommittee. We are delighted to welcome you to the committee.

You may proceed, gentlemen.

STATEMENT OF DR. HENRY E. SIMMONS, DEPUTY ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; ACCOMPANIED BY DR. G. DONALD WHEDON, DIRECTOR, NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES, NATIONAL INSTITUTES OF HEALTH; AND DALE SOPPER, LEGISLATIVE OFFICER, OFFICE OF DEPUTY ASSISTANT SECRETARY FOR LEGISLATION (HEALTH)

Dr. SIMMONS. Thank you, Mr. Chairman. I am here today to present the views of the Department on H.R. 12150, H.R. 14181, and S. 2854,

bills which would amend the Public Health Service Act to expand the authority of the National Institute of Arthritis, Metabolism, and Digestive Diseases, provide for increased activities in prevention, treatment, and rehabilitation of arthritis sufferers, and advance a national attack on arthritis and related musculoskeletal diseases. Let me state at the outset, Mr. Chairman, that we appreciate the interest of the subcommittee as reflected in these bills, but we believe we already have under way an aggressive research effort under existing legislative authority. Accordingly, we feel this legislation is unnecessary and we recommend against enactment for the reasons that I will discuss in my testimony today.

My statement today will highlight our extensive ongoing activities related to arthritis, which are aimed at improving our knowledge of this disease. While the National Institute of Health, through the National Institute of Arthritis, Metabolism, and Digestive Diseases—NIAMDD—bears the major responsibility for research in arthritis, many other institutes are contributing to the expansion of our knowledge on arthritis.

The National Institute of Arthritis, Metabolism, and Digestive Diseases and various other organizations and institutions have been supporting and conducting research on arthritis for a number of years. A great deal is known about the disease. Nevertheless, this disorder is as yet not fully understood and its long-term clinical effects are still not adequately controllable. Original, new research ideas and their translation into productive research studies are the most critical needs. Our efforts are concentrated on the much needed new research ideas and studies, upon which advances in the area of arthritis therapy and prevention can be based. For this reason, emphasis on research on arthritis will be continued, both at the National Institutes of Health in Bethesda and throughout the United States in the scientific community, supported by Federal and private sources.

NATURE AND IMPACT OF ARTHRITIS

Before discussing in detail the legislative proposals before us, I would like to describe briefly for you the nature and scope of the diseases commonly combined together under the term "arthritis," the public health problem they represent, and our current research and other activities in this area.

The term arthritis refers to inflammation and destruction of joints and, specifically, of their lining. Rheumatism, a more general term, usually refers to symptoms from tissues outside the joints, such as muscles, tendons, bones, and nerves.

The American Rheumatism Association, the professional society of arthritis specialists, and the Arthritis Foundation list about a hundred disorders under the combined heading of arthritis and rheumatism, and group them in 13 different categories. Among the major categories are: arthritis of unknown cause (such as rheumatoid arthritis and ankylosing spondylitis); degenerative joint disease (osteoarthritis); connective tissue disorders such as systemic lupus erythematosus; infectious arthritis; traumatic arthritis; and arthritis associated with biochemical abnormalities, such as gout. Each disorder is a

distinct disease entity, but all have one feature in common—pain and/or limitation of function in the joints or surrounding tissues. With your permission, Mr. Chairman, I will include for the record a more detailed description of the various types of arthritis and the outlook in research and therapy.

The Arthritis Foundation estimates that 20 million Americans have some form of arthritis or rheumatism. The degree of discomfort and disability associated with the condition varies from discomfort sufficient to cause complaints to total disablement for some unfortunate patients. Approximately 13 million Americans have osteoarthritis of some degree, and an additional estimated 5 million have rheumatoid arthritis. Approximately 1 million persons have gout, and an estimated 1 million persons suffer from other specific rheumatic conditions including the so-called collagen diseases, many of which have an unpromising prognosis.

In contrast to the so-called killer diseases—cancer, heart disease, and stroke—arthritis is not the cause of a great annual death toll; its toll in terms of pain and chronic disability, however, can be substantial. The extensive human suffering caused by arthritis is matched by its economic cost to the community which has been variously estimated by the Arthritis Foundation to be $4 billion annually and to which an additional billion dollars of direct medical costs must be added.

CURRENT ACTIVITIES OF THE NATIONAL INSTITUTES OF HEALTH (NIH)

A major reason for the establishment in 1950 of the National Institute of Arthritis, Metabolism, and Digestive Diseases—NIAMDD—was to focus the national research effort on the problem of arthritis. Since its establishment, the Institute has underwritten a major effort in research and research training related to arthritis. The current effort directly related to arthritis in NIAMDD amounts to $14 million in fiscal year 1974, most of which is used to fund arthritis research at university centers, medical schools, and hospitals throughout the country.

As I mentioned earlier, it is important to point out that the Institute and other institutes at the NIH expend considerable additional sums in support of arthritis-related orthopedic surgery research and much fundamental research which has varying degrees of direct and indirect relationships to arthritis and which constantly adds to the knowledge needed to understand the disease, without which the final solution to the problem of arthritis would not be possible.

For example, aberrant immune reaction in rheumatoid arthritis causes local damage to the joint; therefore, research supported and conducted by the National Institute of Allergy and Infectious Diseases in fundamental immunology is very important and relevant. Additionally, it is suspected that the initial predisposing process which precedes this abnormal immune reaction is an invasion by an as yet unidentified virus. Advances by the National Institute of Allergy and Infectious Disease—NIAID—and the National Cancer Institute in fundamental virology will be important for future pinpointing of the precise cause.

I believe it will also be of interest to you that NIAMDD, in an effort to facilitate rapid communication of research efforts to researcher and

practitioner alike, to assist ongoing research, and to avoid possible duplication of effort, pioneered the publication of a unique monthly "current awareness" journal, Arthritis and Rheumatic Diseases Abstracts, which was distributed widely to rheumatologists and provided abstracts of the latest publications of research results in arthritis originating anywhere in the world.

One may liken this effort in coordination of the latest knowledge about the disease to constant communications from a central data bank on arthritis. At the present time, since a similar commercial publication has become available in this country, the Institute is no longer distributing its own publication, which had earned widespread praise from the community of research workers and practitioners in the field of arthritis.

In addition, the Institute, through its public information activities, provides the lay public with brochures and information on the disease and, with the aid of radio spot announcements, informs the public of their availability.

PROPOSED LEGISLATION

The legislation you are considering today would:

Require the establishment of a National Commission or Task Force on Arthritis to formulate a long-range plan to combat arthritis and related musculosketal diseases. The arthritis plan developed by this group would provide for broad, coordinated programs of research related to numerous facets of arthritis, encompassing fundamental studies, social, environmental, and epidemiological investigations, clinical studies, and therapeutic trials and investigations of how to provide optimal service to arthritis patients on a community level;

Provide authority for programs for the education and training of relevant professionals, for continuing education of health and allied health professionals, public education, and for the development of a national data storage bank on arthritis;

Establish the position of Associate Director for Arthritis within the National Institute of Arthritis, Metabolism, and Digestive Diseases, and an Inter-Institute Arthritis Coordinating Committee within the National Institutes of Health; S. 2854 would additionally establish an Interagency Technical Committee on Arthritis within the Federal Government;

Authorize the establishment of arthritis screening, early detection, prevention, and control programs;

Establish an arthritis screening and detection data bank;

Authorize National Arthritis Research and Training (or Demonstration) Centers; and

Require submission of reports to the Congress, outlining numerous aspects of ongoing and new arthritis-related activities.

DEPARTMENT POSITION

The Department opposes enactment of such legislation. The research effort against arthritis is appropriately supported at current funding levels, and available scientific opportunities, we believe, are being exploited. The authorities in H.R. 12150, H.R. 14181, and S. 2854 are duplicative and unnecessary.

At present the rate of research advanced against this serious disorder is determined primarily by the difficult nature of the subject matter under study. Future breakthroughs in our knowledge of arthritis may well have to depend on multiple general advances on a broad front of our biomedical knowledge, ranging from the most fundamental aspects of tissue biology on a cellular level and basic immunology through applied clinical advances in orthopedic surgery. As you are aware, research in these fields is also extensively supported in the approximately $2 billion proposed for NIH in the President's budget for fiscal year 1975.

Given the present state of knowledge, the effectiveness of a formalized long-range plan to combat this serious health problem is doubtful and would itself be dependent on new research ideas and advances. Without these and since outright prevention of the disease is currently impossible at the present state of our knowledge, such a plan should not now be mandated.

With respect to arthritis control programs and the demonstration centers, we believe that categorical Federal support for such activities is not needed. The programmatic basis for singling out arthritis for a new Federal effort has not been established. In addition, there are serious doubts that any early detection and screening programs would in any way enhance our ability to treat these diseases at this time and, therefore, the expense of establishing these programs would not be warranted. A large coordinated research effort is already mounted in the field of arthritis as well as in related fields, from which much of the newer knowledge concerning the mechanisms of the disease is expected to evolve.

We believe that research in arthritis is being given priority consistent with available research opportunities and consistent with other Federal research priorities. There already exists an effective informal network of arthritis communications within the NIH and among Federal departments, including those specified in S. 2854. Ample authority to expand and to formalize such communications is already in place. Accordingly there is no need for statutory authority to create additional arthritis coordination committees. Similarly, the statutory creation of an Associate Director for Arthritis within the NIAMDD is unnecessary.

I would also add, Mr. Chairman, that we oppose this legislation for another reason as well. The President's Biomedical Research Panel will, within the next year and a half, be carefully examining overall national health research priorities. The panel, established by the National Cancer Act Amendments of 1974, will review, assess, identify, and make recommendations with respect to policy issues concerning the subject and content as well as the organization and operation of all biomedical and behavioral research conducted and supported by the National Institutes of Health. It would be important to have in hand the Panel's recommendations which will be based on a comprehensive view of NIH organization and operations in the context of the Public Health Service before broadening the NIH mission or changing its organization in individual programs such as arthritis.

The appropriations authorizations in these bills are also unnecessary since under current law there are no specific limits on the appropriations that can be made for arthritis-related activities.

CONCLUSION

In conclusion, as I stated earlier, we believe that research in arthritis is being given priority consistent with available research opportunities and consistent with other research priorities. Undoubtedly, a large fundamental research effort in the relevant related fields and in arthritis-related orthopedic surgery is an essential contributing factor for eventual breakthroughs in arthritis. A strong effort along these lines is, however, currently being undertaken by the NIAMDD and other NIH institutes.

In sum, the Department feels that the major purpose of the proposed legislation is already well served by existing activities and legislative authority for research directed toward the cause, prevention, diagnosis, and treatment of arthritis. We therefore recommend that new legislation not be enacted.

We wish to thank you, Mr. Chairman and members of your subcommittee, for the opportunity to appear before you to testify on a subject which is of unquestioned importance to our population and of great concern both to the Congress and the administration. We will be happy to take your questions.

[The attachment to Dr. Simmons' prepared statement follows:]

ARTHRITIS

RHEUMATOID ARTHRITIS

Rheumatoid arthritis is the most crippling of the various types of arthritis. Although it does most of its damage to the joints, the disease primarily affects the body's connective tissues. These tissues connect and support the specialized components and organs of the body. They include such elements as membranes, tendons, ligaments, bone, and cartilage.

Many body organs may be affected in rheumatoid arthritis, and there are constitutional symptoms such as weakness and loss of weight. The disease begins with inflamatory changes and sweiling in the membrane lining the joint. Inflamed tissue encroaches upon the joint surfaces, causing pain, limitation of motion, and deformity.

Rheumatoid arthritis is three times more prevalent in women than men, and usually begins between the ages of 35 and 50, but people of all ages are susceptible from early infancy through old age. Studies of its incidence in certain populations indicate that the disease afflicts 2.5 to 3 percent of the general population, and about 10 percent of this number are very severely affected. The disease has been found in all parts of the world.

Although the cause of rheumatoid arthritis is still unknown, productive research during recent years has uncovered important information related to it. In seeking its cause, scientists have studied many different possibilities. Some have been tentatively ruled out, while other more promising leads are being investigated intensively.

Most research attention is focused on two theories. One is the concept of autoimmunity, which holds that the body, for unknown reasons, produces abnormal antibodies that are directed against its own tissues rather than against foreign material. Part of the evidence supporting this concept is the abnormally high level of certain types of gamma globulins (antibodies) in the blood of rheumatoid arthritis patients.

The other theory, that an infectious process may be responsible, could tie in with the autoimmunity concept, because it may be an infectious agent that triggers the production of these antibodies. Although no causative organism has yet been pinpointed, many regard the evidence as very suggestive.

OSTEOARTHRITIS

Much more common than rheumatoid arthritis, but less damaging, osteoarthritis is characterized mainly by degeneration of joint cartilage. The cartilage

becomes soft, wears unevenly and, in some areas, may wear away completely, exposing the underlying bone. Thickening of the bone ends also may occur. The rest of the body is seldom affected and, except in some cases involving the hip joints, the disease causes no severe deformity or crippling.

Osteoarthritis occurs almost exclusively in middle-aged and elderly persons. It is more prevalent in women than men, and women commonly have their first symptoms at the time of the menopause.

Common symptoms are pain and stiffness. Pain is usually experienced during use of the joints, especially finger joints and those that bear the body's weight. Enlargement of the fingers around the last joint often occurs. Although permanent, these enlargements, or nodes, usually do not lead to disability.

Two concepts have been formed about the development of osteoarthritis. One puts the blame on mechanical stress and the other implicates biochemical factors.

The mechanical concept holds that osteoarthritis results from a combination of aging, irritation of the joints, and normal wear and tear. Chronic irritation of the joints is believed to be the main contributing factor. This may come from overweight, poor posture, injury, or mechanical strain from one's occupation or recreation.

The biochemical concept implicates hereditary, metabolic, and endocrine factors. Laboratory research has demonstrated the importance of heredity in the development of osteoarthritis in mice.

GOUT

One important cause of acute, very painful, and sometimes chronic destructive arthritis is gout, an inherited metabolic disorder associated with a buildup of uric acid and its salts in the blood and tissues. This material crystallizes and accumulates in and around the joints, resulting in inflammation, severe pain, and eventual destruction of normal joint structure.

Today, of all the arthritic diseases, gout can be controlled the best. Research conducted and supported primarily by the NIAMDD during the last 15 years has elucidated the causes and mechanisms of gout and has enabled us to bring this disease under control once it is diagnosed. Highly effective drugs developed during the past decade are used to rid the body of its excess uric acid via the urine or to forestall its formation in large quantities, thus preventing a buildup of harmful crystal deposits. Present research emphasis is on developing methods for early diagnosis and further improvements in treatment so that deformity and complications can be fully prevented.

PSORIATIC ARTHRITIS

Arthritis affects eight to 10 percent of patients with psoriasis, a fairly common skin disease. The arthritis that accompanies psoriasis usually resembles the rheumatoid type, and it is treated in a similar manner. Special attention is given, of course, to treating the skin condition.

It is still not known what causes the psoriasis or the arthritis. There is some evidence that psoriasis may be hereditary, but this has not yet been proven conclusively. Evidence has also been found that disordered metabolism of nucleic acids may play an important role in the disease.

SYSTEMIC LUPUS ERYTHEMATOSUS (SLE)

A grave, generalized disease of connective tissue, SLE is manifested by structural and functional changes in the skin, joints, and internal organs. It is found most often in the 20–40 year age group, affecting women more frequently than men. Although certain measures can be taken, there is no specific and complete treatment for this disease which, in the long run, has a grave prognosis.

ANKYLOSING SPONDYLITIS

Also known as rheumatoid spondylitis or Marie-Strumpell's disease, this systemic disorder primarily affects men in their late adolescent or young adult years. It is characterized by back pain, stiffness, and progressive loss of function resulting from involvement of spinal joints.

Mr. ROGERS. Thank you very much, doctor, for your statement on behalf of the Department. Mr. Preyer.

Mr. PREYER. Mr. Chairman, I have no questions at this time. I gather Dr. Simmons' position is that they have a sufficient research effort underway and additional legislation is not needed. Perhaps other testimony will throw more light on that subject. Thank you, Mr. Chairman.

Mr. ROGERS. Mr. Carter.

Mr. CARTER. Thank you, Mr. Chairman. Dr. Simmons, what is the cause of rheumatoid arthritis?

Dr. SIMMONS. We don't know.

Mr. CARTER. You don't know. Who was Dr. Hans Selye?

Dr. SIMMONS. He was a noted biologist and researcher who was very important in a number of areas.

Mr. CARTER. What was he famous for?

Dr. SIMMONS. Well, stress, for one, and many other things.

Mr. CARTER. What did he find out from stress?

Dr. SIMMONS. Again, there was so much, I am afraid I really couldn't be more helpful than that.

Mr. CARTER. Did it have to do with the suprarenal gland?

Dr. SIMMONS. I am sure that was one of his hypotheses.

Mr. CARTER. Did he think that led to, or in some cases was the cause of, arthritis?

Dr. SIMMONS. I am not familiar enough with that particular work to know for sure.

Mr. CARTER. What do you know about the first time that cortisone was found? What can you tell me about that?

Dr. SIMMONS. Well, I can only tell you that Philip Hench was the person to first apply such therapy, over 20 years ago now. He is an alumnus from the school I was graduated from and, since my background is rheumatology, I became familiar with his work.

Mr. CARTER. What was the basis? How did he happen to find it?

Dr. SIMMONS. Through clinical therapy.

Mr. CARTER. Isn't it true that he found out that pregnant women do not have rheumatoid arthritis; is that not correct?

Dr. SIMMONS. I don't know. I don't believe that is an accurate statement.

Mr. CARTER. I believe that is quite true. I think that Dr. Whedon might be able to help you on that a little bit; and actually, from examining the urine of pregnant women, we found this substance, which, in some cases, is helpful to treatment of rheumatoid arthritis but which may have disastrous effects also.

Do you think we have done enough research on this particular element which does give relief in many cases to victims of rheumatoid arthritis? Do you think we have researched this enough? Do we know enough about that?

Dr. SIMMONS. It is always tough to answer "Have we done enough?" on anything. Our basic position is that we have developed a research program that is following the leads that are available to us. And there is a second part of that, one which is extremely important: Given all the leads that face us throughout research, we have to set some priorities. And we believe that, given those two provisos, we have an adequate effort mounted in this area. Is there enough? There is probably never enough even if we consumed all the societies' resources in narrow fields.

Mr. CARTER. How much do we spend each year, Dr. Simmons, for research in heart disease?

Dr. SIMMONS. Well, as you know, the total NIH budget is about $2 billion, and I guess heart this year in the President's original budget is about $300 million.

Mr. CARTER. Cancer is how much?

Dr. SIMMONS. About $600,000 in the President's original budget.

Mr. CARTER. Each year we lose 350,000 people from cancer; is that correct?

Dr. SIMMONS. It is someplace in that order.

Mr. CARTER. In all that time, we have from 4 to 5 million people suffering from rheumatoid arthritis. Then really if we consider the factors of morbidity and economic impact, $14 million is really not much, is it, for this disease which affects as many people as cancer and heart disease? It is a drop in the bucket.

You are spending $14 million now. Where are you spending this money?

Dr. SIMMONS. I can have Dr. Whedon give you that.

Dr. WHEDON. The funding in this effort is in arthritis research. The major part of it goes out in support of research grants to universities and medical centers throughout the country. Within our own institute in Bethesda and our laboratories and our clinical research beds there, our effort amounts to about $2 million.

Mr. CARTER. About $2 million.

Dr. WHEDON. Right, and a smaller amount, of course, is now spent in support of training—$81.7 million in 1974. Much smaller amounts are spent as part of our effort in learning more about the epidemiology of these diseases.

Mr. CARTER. Last year how much did you spend on arthritis?

Dr. WHEDON. The total figure in fiscal year 1974 for arthritis was $13,941,000.

Mr. CARTER. $13 million, and the year before that?

Dr. WHEDON. The year before that it was $13,800,000. In addition, however, there were some funds which were released as a result of congressional action which provided an additional $1,700,000 for arthritis research. The released funds of 1973 were actually outlaid in 1974.

Mr. CARTER. But really we just haven't found the cause of rheumatoid arthritis, have we?

Dr. WHEDON. That is correct, Dr. Carter. However, we do feel that we are making strides in this direction.

Mr. CARTER. What are these strides?

Dr. WHEDON. The principal work that is going on that is, I think, outstanding in this area has to do with understanding immunology. There is an altered or inappropriate human immunologic response which occurs in patients with rheumatoid arthritis. As the title of one of our projects has it, we are working on and making progress on the mechanism of immune injury. This is now felt to be the basic problem in development of rheumatoid arthritis, the instigating episode presumably being an infection with some agent, possibly a virus.

Mr. CARTER. Possibly a virus. Don't you think actually that lack of immunity might well be due to the insufficiency of the suprarenal gland?

Dr. WHEDON. Clearly the reaction of adrenal cortex is related here as evidenced by the effects of administering adrenal hormonal material to patients with rheumatoid arthritis, but it is not effective in all patients; and also, even in those patients to whom it is given, there are very serious side effects.

Mr. CARTER. I believe I mentioned that, very disastrous. You certainly can't use it regularly, can you?

Dr. WHEDON. However, we think that it is important for us to try to get at more fundamental aspects of the development of this disease, and that is why we are stressing research in immunology.

Mr. CARTER. I will certainly agree with you that we certainly should get at the fundamental aspects. One of them is that consistently the levels of production of adrenal cortex are lower. We know that. And then there are so many other factors. We don't know whether it is a virus—which I doubt seriously; it may be—or just what it is that causes it. But we do know that some excellent responses have been secured in some cases by use of a cross spectrum of antibiotics. Do you know that to be correct?

Dr. WHEDON. I am aware of this work. It has been going on for a long period of time. I think it is not really conclusive, however.

Mr. CARTER. I know; that is one of the attitudes that we have. But I have seen in work. As I mentioned before I observed a youngster with Still's disease go into complete remission, and that youngster has been in remission for several years now.

Unfortunately, I doubt if we regard some of the information we get as meaningful as it really is. But I know it is, because I have seen it work.

We desperately need these funds for this. To say that we don't need this authorization—well, I am surprised. Thank you, Mr. Chairman.

Mr. ROGERS. Mr. Heinz.

Mr. HEINZ. Mr. Chairman, I have no questions at this time.

Mr. ROGERS. Mr. Symington.

Mr. SYMINGTON. No questions.

Mr. ROGERS. How many cases of arthritis were there in the United States in 1961 to 1963?

Dr. WHEDON. The number of cases estimated at that time was in the neighborhood of 14 million. These are all forms of arthritis and represent the figure for those individuals who come to a doctor for one reason or another related to disease of the joints or those who replied positively to questions concerning arthritis symptoms in survey questionnaires.

Mr. ROGERS. I understood the U.S. Public Health Service published a figure of 12,868,000. Would that be——

Dr. WHEDON. I would accept that.

Mr. ROGERS. How many cases of arthritis from 1969 to 1970?

Dr. WHEDON. I don't know that figure. I remember the figure of 17 million being in use about that time.

Mr. ROGERS. The U.S. Public Health Service says 20 million. Now it appears that there has been an increase of 7½ million cases of arthritis in just a 7- or 8-year period, almost a 60-percent increase. Is there any reason for this that we know of? How do we reconcile this, Dr. Simmons, all this increase, and yet we seem to be doing enough?

Dr. SIMMONS. I am not sure we can infer that is a true increase, Mr. Chairman. You know the problems of statistical systems.

Mr. ROGERS. It is the best knowledge we have, isn't it?

Dr. SIMMONS. Right, but what I mean is: I think it would be dangerous to infer there has been an epidemic increase in the disease as opposed to possibly better diagnostic methods.

Mr. ROGERS. What makes you draw that conclusion?

Dr. SIMMONS. Because I have seen it consistently throughout public health statistics. As we screen better and develop new diagnostic methodology, we find more cases that were there all the time. I am not saying that is necessarily the case here, but it is one thing we should consider.

Mr. ROGERS. You mean we didn't know in 1961 or 1963 about arthritis?

Dr. SIMMONS. We know more about it now than then.

Mr. ROGERS. What more do we know now? Do we know how to cure it?

Dr. SIMMONS. We don't know how to cure it. We have advanced in how to treat it and diagnose it and in the field of immunology. I believe we have made advances there.

Mr. ROGERS. What are we treating it with—aspirin?

Dr. SIMMONS. No; we don't have the cure. I don't know when we will achieve that.

Mr. CARTER. Would you go over your treatment for arthritis if you would, please, sir?

Dr. WHEDON. I will be glad to speak to that. The treatment of arthritis, particularly with respect to rheumatoid arthritis, is varied and there are a number of measures that are available. Aspirin in considerable dosage is useful.

Mr. ROGERS. It doesn't cure it, but it helps the pain, doesn't it?

Dr. WHEDON. Presumably, it really is believed to do more than simply attack the pain and, in association with physical therapeutic techniques, for many it has been useful. In other cases, gold salts——

Mr. CARTER. If the gentleman would yield, on aspirin, isn't it true it is somewhat chemically related to cortisone?

Dr. WHEDON. There has been some evidence to suggest that some part of the reaction of aspirin may be along these lines of stimulating release of cortisol from the adrenal gland.

Mr. CARTER. You know, I feel that cortisone could be perfected so that it would not cause all the side effects, and perhaps that might be an area you could look at.

Dr. WHEDON. I would agree, Dr. Carter. When cortisol was introduced in 1958 and 1960, the results were spectacular, and we had great hopes that we could make a tremendous advance in time.

Mr. ROGERS. I see people wearing copper bracelets. Do you go for that, too?

Dr. SIMMONS. Not officially.

Dr. WHEDON. I would be delighted to have that question referred to some colleagues who will follow later.

Mr. ROGERS. I didn't know whether the Department had taken a position on that or not. If you have, I think it would be interesting to have it for the record.

Dr. WHEDON. I was once asked, Mr. Chairman, by a very attractive Member of the House of Representatives my opinion on copper bracelets. She held up her arm to show me one and said, "What do you think of it?" I said it was charming.

Mr. CARTER. Mr. Chairman, on that very thing, we had an eminent professor of medicine testifying before our committee—I believe he is from Harvard—and he was wearing one of those bracelets at the time.

Back on the gold therapy which the gentleman mentioned, I believe actually you get remission in about one out of eight cases, about 12½ percent; is that correct?

Dr. WHEDON. Dr. Carter, I am not familiar with the specific statistics. I know only that the use of gold salts is regarded as one of the principal methods of therapy.

Mr. CARTER. What is the mechanism of its action?

Mr. WHEDON. I am not familiar with how gold salts are believed to work.

Mr. CARTER. Perhaps Dr. Simmons could tell us.

Dr. WHEDON. I think we have some experts following us who can delineate that and take you through that in any detail you would like.

Mr. ROGERS. If you would continue for the record putting down the treatment. Do you use hot paraffin still?

Dr. WHEDON. I believe this is used in some instances, yes. I have not been close to the clinical treatment of arthritis in some time. I am not certain of that but I believe so. I will be glad to expand for the record, sir.

[The following statement was received for the record:]

Immersion treatment with hot paraffin is used in some instances as part of the physical therapy which is helpful in amellorating the pain and stiffness. It also permits the patient to initiate joint exercises more easily.

Injection of gold salts is currently our most effective long-term drug treatment in rheumatoid arthritis and helps about 60 percent of patients.

The specific mechanism of action of gold compounds is still an enigma.

Mr. ROGERS. How many deaths from arthritis were there in 1969? They estimate 4,908. Do you know how many were in 1973, 1970, 1971, 1972?

Dr. WHEDON. I don't have that figure available, Mr. Chairman.

Mr. ROGERS. Do we know in 1974 how many there have been?

Dr. WHEDON. I believe that figure is obtainable and I believe it is of the same general magnitude as you have cited.

Mr. ROGERS. I don't have those figures. Could we get them? I don't know they are available.

Dr. SIMMONS. I imagine the National Center for Health Statistics might have them. As you know, death is a rare event in arthritis. It is a major problem in its morbidity.

Mr. ROGERS. This, I guess, has been listed as the underlying cause of death—these that are considered arthritis deaths.

Dr. SIMMONS. I would imagine they might be referring there to systemic lupus erythematosus and like syndromes.

Mr. ROGERS. I figure about 853 in 1969. In other words, I don't think we have any figures that have been assembled since that time. So if you do have them, we would like to have them.

[The following information was received for the record:]

Deaths due to "Arthritis" [1]

1969	1,948	1972	1,966
1970	1,930	1973	2,043
1971	1,916		

[1] ICD codes 710–715, which excludes lupus erythematosus.
Source: National Center for Health Statistics, USPHS.

Dr. WHEDON. Mr. Chairman, the National Center for Health Statistics in its Division of Health Examination Statistics and its Division of Health Interview Statistics is in the process of getting ready to go out and make detailed observations that would provide information along these lines. They do this periodically and they are coming to another phase where they will undertake detailed surveys.

Mr. ROGERS. Who is doing that?

Dr. WHEDON. These are two divisions in the National Center for Health Statistics, which is part of the Department of Health, Education, and Welfare.

Mr. ROGERS. But they haven't done that on a continuing basis?

Dr. WHEDON. No; it is their system to do this in cycles of about every 4 to 5 years. It takes quite some time to tool up to do these surveys and interviews in a meaningful, reliable way.

Mr. ROGERS. How can we make judgments on what we should take when we really don't have basic facts?

Dr. SIMMONS. We have a substantial body of basic knowledge, Mr. Chairman, on rheumatoid arthritis, and I think you can lay out a fair body of information to back it.

We don't have all the answers certainly but we certainly have a disease here that we handle better now than we have in the decade prior to this. It is certainly a long way to go.

Mr. ROGERS. How much direct research for arthritis is being done in other institutes than the National Institutes of Health in 1974?

Dr. WHEDON. There are a number of activities in other institutes: in the National Institute of Allergy and Infectious Diseases——

Mr. ROGERS. With the direct purpose of helping the arthritis problem?

Dr. WHEDON. No; I would say the work done in the other institutes is all closely related but they are not directly related. In the General Medical Sciences Institute they do a lot of work in genetics, pharmacology, and toxicology, which are related.

Mr. ROGERS. Of course, you can say that about every disease, I presume, so you hook in on that?

Dr. WHEDON. Well, it is a sound principle in the study of many diseases.

Mr. ROGERS. I understand, certainly, but we are thinking of zeroing in a little bit and having it more direct.

Mr. SYMINGTON. Mr. Chairman.

Mr. ROGERS. Yes.

Mr. SYMINGTON. In that connection, it seems that the statistics indicate that 90 percent or more adults over 60 have recognizable signs of arthritis. Is that in accord with your understanding? It can be visibly seen with X-ray?

Dr. WHEDON. A very high proportion of patients in the older category do have osteoarthritis.

Mr. SYMINGTON. I am wondering if you have conducted studies on a systematic basis as to which point in the aging process it is most likely to occur and then studies to determine what are the characteristics of diet or work and play that have made an impact on the likelihood of arthritis occurring that would give our society a chance to spot danger signals and move on it earlier in life. Have you any studies of that kind?

Dr. WHEDON. Well, our institute is supporting studies of this nature in osteoarthritis. It is not an extremely exciting aspect of the study of this disease but such observations are going on and we are hopeful that leads will be resulting from this work.

Mr. SYMINGTON. Mr. Chairman, I have a letter from the head coach of the Saint Louis football Cardinals, Don Coryell, a letter requesting the committee to act on this bill if we possibly can, and I would very much like to make it part of the record at this point.

Mr. ROGERS. Without objection, it is so ordered.

[The letter referred to follows:]

ST. LOUIS FOOTBALL CARDINALS,
St. Louis, Mo., November 19, 1974.

Congressman JAMES SYMINGTON,
Congress of the United States, House of Representatives, 307 Cannon Building, Washington, D.C.

DEAR MR. SYMINGTON: I am writing this letter in support of the National Arthritis Act in hopes that you will do everything possible to urge its passage during the 1974 Session. Perhaps a word from you to Representative Paul Rogers would help to get this Act on the agenda before the 1974 Session ends.

Thank you for your consideration in this matter.

Sincerely,

DON CORYELL, *Head Coach.*

Mr. SYMINGTON. He is flagging these problems. He has seen young people with relevant problems in the athletic world, and it would seem to me this is high time the Nation moved on this with some focus.

Mr. ROGERS. Thank you.

How many clinical beds within the Institute are devoted to arthritis exclusively?

Dr. WHEDON. We have a total in the Institute of 68 beds and, I believe, 15 of those beds are devoted to arthritis.

Mr. ROGERS. How many people are devoting their full time to arthritis?

Dr. WHEDON. I have that information right here. We have at the present time 37 people who are working on arthritis within the Institute.

Mr. ROGERS. Full time?

Dr. WHEDON. Full time. This is total man-years.

Mr. ROGERS. How many individuals does that represent? Not man-years, but how many individuals would that represent?

Dr. WHEDON. It is virtually the same thing.

Mr. ROGERS. Thirty-seven?

Dr. WHEDON. Probably I should be more specific, Mr. Chairman. It undoubtedly does mean something in the neighborhood of perhaps 45 to 50 altogether, because some people would be spending some time on arthritis and some on other activities.

Mr. ROGERS. How much money has been expended for intramural re-

search on new orthopedic procedures for treatment such as for the joints?

Dr. WHEDON. The answer to that, Mr. Chairman, is that we have no intramural orthopedic research in our section.

Mr. ROGERS. None?

Dr. WHEDON. Not at the present time.

Mr. ROGERS. Should we have?

Dr. WHEDON. I think this would be useful and in order. I would like to say two things about this: First, that we do have some work in the Metabolic Disease Branch in the Mineral Metabolism Section, which I headed at one time, which continues to be interested in osteoporosis. This is the most common disorder affecting the bone, at least in older individuals.

The other aspect, I would say, is that our failure to have an orthopedic research section intramurally is not from our lack of interest or desire but from the restraints placed upon us in space and the number of people available for work. And, of course, these are really the main constraints that we have generally in our intramural research.

Mr. ROGERS. Funding, surely?

Dr. WHEDON. Well, it is less funding than it is ability to have people and a place in which they can work. There is a limitation in space, in the number of beds in the number of laboratories, a finite limit in relation to the very broad responsibilities that we have and that all the other institutes have among many, many diseases. So we have to make choices.

Mr. ROGERS. I know you are not using all available space in your Clinical Center.

Dr. WHEDON. I know of no laboratory space in the Clinical Center or anywhere on the NIH campus which is not in use. There are some beds which, of course, are not filled.

Mr. ROGERS. Wards.

Dr. WHEDON. That is partly because of the fact that hardly any hospital has completely filled beds. The other is a restraint related to getting enough nurses. We have a distinct shortage of nurses in the Clinical Center.

Mr. ROGERS. I understand that.

Now, you say you can't do it because you don't have any lab space. Have you tried to contract for any lab space?

Dr. WHEDON. No, we have not, Mr. Chairman.

Mr. ROGERS. I presume it could be done if this bill passes and if we give you the support to do that. I presume you could do it.

Dr. WHEDON. Yes, and I would say again, Mr. Chairman, that we clearly are interested in orthopedics and, to whatever extent we can fit the activity within our resources, we would be glad to do so.

Mr. ROGERS. As a matter of fact, they are making rather significant gains in this area, are they not?

Dr. WHEDON. Yes; the work on artificial joints has been really outstanding in recent years. An artificial hip operation is commonly done and now a lot of work is being done on artificial knees and other joints. Much of this work has been carried out with support from us.

Mr. ROGERS. You are not spending any money intramurally for this purpose at all?

Dr. WHEDON. That is correct, sir.

Mr. ROGERS. Where have the most significant gains been made in the orthopedic area or otherwise contributing to the relief of arthritis?

Dr. WHEDON. The outstanding development recently in the orthopedic area is the one I just mentioned, artificial joint replacements. This is particularly valuable in osteoarthritis.

Mr. ROGERS. Which affects about 12 million?

Dr. WHEDON. Yes.

Mr. ROGERS. Well, this is what I am concerned with. Here are 12 million people and we are not doing anything intramurally. That doesn't sound like an active program.

Dr. SIMMONS. I think the point Dr. Whedon made is important. We have supported research in that area.

Mr. ROGERS. To what extent?

Dr. SIMMONS. I can't give you the exact dollar amount.

Mr. ROGERS. Well, Dr. Whedon can perhaps give us that.

How much of your money has gone into research in this area?

Dr. WHEDON. The total funding of research and training grants in the orthopedic bone disease area in 1974 was $7,240,000.

Mr. ROGERS. How was the rest of your money spent?

Dr. WHEDON. In our total institute, the remainder goes to a wide variety of diseases.

Mr. ROGERS. No; I am speaking just in the arthritis field.

Dr. WHEDON. In the arthritis field—well, the rest of our funding is in the arthritis operation which we mentioned earlier, on the level of $14 million.

Mr. ROGERS. That is total. What I am saying is, how is the $14 million spent? You say $7 million has been in grants.

Dr. WHEDON. $7 million is in research and training grant support in the orthopedic area. In addition to that there is about $11 million in research and training grants in the arthritis area, apart from the intramural work carried on in Bethesda (about $2 million).

Mr. ROGERS. What I am trying to get at is exactly what is being spent on just arthritis?

Dr. WHEDON. $14 million in 1974, $2 million of which was intramural arthritis research.

Mr. ROGERS. Now, the $7 million is part of the $14 million or not?

Dr. WHEDON. No; it is in addition to.

Mr. ROGERS. But you don't classify that as geared or directed to arthritis?

Dr. WHEDON. We are merely giving it as a breakdown, Mr. Chairman. The total of arthritis and bone research and training all together in 1974 was more than $21 million.

Mr. ROGERS. I understand, but I am saying you did not put that out as arthritis research?

Dr. WHEDON. No; we did not.

Mr. ROGERS. What I am wondering is what you are spending on arthritis research, because this bill will go to that. It is not ancillary. It would be primarily and directly for arthritis.

Now, you have $14 million of which $2 million is intramural.

Dr. WHEDON. That is correct.

Mr. ROGERS. How much of the $14 million went to the osteoarthritis?

Dr. WHEDON. In osteoarthritis. I would have to estimate but it would probably be in the nature of a half million.

Mr. ROGERS. That is what I wanted to get at. Half a million for 12 million people.

Dr. SIMMONS. As you know, it is extremely difficult to break it down by disease category because the mechanism may not apply at all.

Mr. ROGERS. I understand that, but it is also very easy to break it down because that is the way they are doing it in grants. If it goes to arthritis we want a direct program, a direct research; it goes right there and that is the way it is handled and it comes out of that pot of money.

What we are saying is that we want to know what is being done so we know how to give a boost. You say we don't need it.

Dr. SIMMONS. You were asking for a breakdown by the specific diseases and I caution that will be difficult for us to do, but we will try to break it down to those specifics for the record.

Mr. ROGERS. I don't know why it is difficult to do.

Dr. SIMMONS. The point is that we may be funding a basic research program in metabolism which in fact impacts on all the kinds of arthritis we are dealing with.

Mr. ROGERS. It may impact on other things as well. But just for arthritis, this is what we are zeroing in on. I realize we are doing basic research all over NIH. Everything that is done could be said to have some impact here. I realize that. What we are trying to do is find out what is specifically designated for arthritis. That is what this bill does, zeros in and tries to put emphasis. I don't think what we are doing puts much emphasis on arthritis.

Dr. WHEDON. Mr. Chairman. I will be glad to supply the figures with regard to the breakdown of research in gout and osteoarthritis and rheumatoid arthritis and other forms of arthritis.

[The following information was received for the record:]

NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES

Extramural research grants in arthritis—fiscal year 1974

Causation, therapy, pharmacology, and metabolism of arthritis	$330,000
Rheumatoid arthritis and immunologic derangements in arthritis	1,759,000
Juvenile rheumatoid arthritis	388,000
Osteoarthritis	420,000
Gouty arthritis	344,000
Other forms of arthritis	271,000
Systemic lupus erythematosus	608,000
Structure and function of muscles as related to arthritis	1,391,000
Cartilage as related to arthritis	179,000
All other supporting tissues and components as related to arthritis	2,653,000
Total	8,343,000

Extramural research grants in orthopedics—fiscal year 1974

Cartilage, joint linings, and bone	1,689,000
Fractures	580,000
Joint structure and function, tendons and ligaments	502,000
Artificial joints and joint and bone transplants	549,000
Diseases of bone	381,000
Scoliosis	53,000
Growth, development and metabolism of bone	1,708,000
Total	5,462,000

Mr. ROGERS. What is the Department of HEW doing to inform the public about the symptoms of arthritis and recommendations and consulting for treatment at an earlier stage? How much does go for public information programs; any?

Dr. WHEDON. We do have some work along those lines. We provide brochures and informational pamphlets with regard to arthritis. We do not have a major public information activity in the National Institutes of Health. This has been more a feature of the work of the Arthritis Foundation.

Mr. ROGERS. How much is spent by the Government for this purpose for arthritis?

Dr. WHEDON. Mr. Chairman, I am not familiar with the specific figure.

Mr. ROGERS. Can you give us a rough estimate?

Mr. CARTER. Hasn't your publication been discontinued?

Dr. WHEDON. Yes; it has. This is a publication which is not broad public information but to coordinate and facilitate the work of physicians——

Mr. ROGERS. Continuing education?

Dr. WHEDON. Yes; it is continuing education in a sense.

Mr. ROGERS. But that has been abolished?

Dr. WHEDON. It was cut out because of the establishment of a competitive journal by a commercial publisher.

Now, Mr. Chairman, I might say that we have heard that this current journal is not as good as the one that we used to have and we are beginning to hear recommendations and, in fact, entreaties that we get back into the publication of this.

Mr. ROGERS. This is what we heard and that is why we thought this bill might have some importance in this area.

Dr. WHEDON. It is a very important thing to do.

Mr. ROGERS. How many rheumatologists are there in the country, would you think?

Dr. WHEDON. I understand that there are in the neighborhood of 2,500 rheumatologists.

Mr. ROGERS. Is that a sufficient number?

Dr. WHEDON. I think it probably is not and I think the feeling is that in many specialties there are not as many experts as there should be. I think we feel the need to attack this problem more effectively, a need for more investigators to be trained, and this is the point of our training programs.

Mr. ROGERS. But there has been a study—I presume you are aware of it—"The Rheumatologists Manpower Study Need."

The estimate is we will need a 630-percent increase in the training capacity for the training of rheumatologists by 1981. Does the Department agree with that?

Dr. WHEDON. I agree with that, Mr. Chairman. I am happy to say that we participated in supporting that Manpower Study along with the Arthritis Foundation.

Mr. ROGERS. Is this reflected in your current program?

Dr. WHEDON. Mr. Chairman, I would have to say that it is not.

Mr. ROGERS. I would agree with you and yet we hope to do something in this bill to lay the foundation for doing something about that 630-percent increase.

Dr. WHEDON. Training is in flux at the present time. We are hopeful of doing more along these lines.

Mr. ROGERS. In fact, in 1965 the Surgeon General had a work shop on prevention disability of arthritis. How many of those recommendations have been carried out, would you say, Dr. Whedon?

Dr. WHEDON. I feel certain that a number of them have, within our capability. I am not immediately familiar with the specific recommendations made in 1965.

Mr. ROGERS. I think it would be helpful for the record if you would let us know what has been done as a result. I feel not very much has been done and I realize you are working in restraints but we are trying to help you change that in spite of some of the feeling.

[The following information was received for the record:]

ACTION TAKEN ON THE RECOMMENDATIONS OF THE SURGEON GENERAL'S WORKSHOP ON PREVENTION OF DISABILITY FROM ARTHRITIS

The Surgeon General's Workshop on Prevention of Disability from Arthritis which took place in 1965 made a number of recommendations the majority of which dealt with comprehensive treatment care programs, community level control and demonstration activities and screening and early prevention work. Recommendations concerning research in the various forms of arthritis (which were in the minority) were indeed followed by the NIAMDD, such as "better studies of the acute stages of arthritis must be made." Research results of the last 8 to 9 years have filled many of the gaps which existed in 1965. Another recommendation stated that "training for and support of better clinical investigation be encouraged." Here again, the Institute has done everything it could within budgetary limits. Total NIAMDD support for arthritis research and training has increased from $8,514,000 in 1965 to $14,076,000 in 1974.

On the other hand, the other recommendations, which dealt with comprehensive care, control and demonstration efforts, screening and surveys (such as "that Federal categorical grants be made for comprehensive community service programs that aid the chronically ill") were not activated because the component of the Public Health Service which had specific responsibility for this type of effort, the Diabetes and Arthritis Program of the Division of Chronic Diseases of the Public Health Service, was phased out during the reorganization of the Public Health Service soon after the Workshop. This reorganization eliminated most categorical (individual disease-oriented) community level programs in favor of broader regional and national non-categorical efforts such as Regional Medical Programs, Comprehensive Health Planning, and others.

Mr. ROGERS. How many medical schools in the United States have arthritis training and research programs? Would 60 be about right?

Dr. WHEDON. No, sir, that is a larger number——

Mr. ROGERS. I think they said 40 but we were being generous and said 60 had some rheumatology in the curriculum. But, only about 11 have comprehensive programs. Would you agree with that?

Dr. WHEDON. At the present time, in 1974, we have 24 training grants in arthritis and 9 training grants in orthopedics. These numbers represent those institutions that have comprehensive, vigorous training programs.

Mr. ROGERS. So most of our medical schools do not have comprehensive programs?

Dr. WHEDON. That is correct.

Mr. ROGERS. Yet, 20 million people are affected annually and we don't even have training courses in the school. Don't you think we need a little more training?

Dr. WHEDON. I think the matter of the content of curricula of medical schools is a matter for them to decide.

Mr. ROGERS. I know it is a matter for them to decide. I am asking you if there is a need?

Dr. WHEDON. I would concentrate my answer on the need for more investigators in the field.

Mr. ROGERS. How do you get them?

Dr. WHEDON. By training programs and fellowships.

Mr. ROGERS. Sure.

Are you planning to go ahead and support arthritis centers?

Dr. WHEDON. We are supporting one center at the present time. We intend generally to support a small number of centers in our various areas of responsibility. These will be highly selected and will be limited primarily to core support, that is, those activities that are needed to coordinate active, vigorous, research projects in certain of our medical centers.

Mr. ROGERS. I assume you don't really oppose the establishment of some of these centers?

Dr. WHEDON. Well, there is a difference in the form of center that we now support. We now support centers which are quite strictly limited to research in these areas.

Mr. ROGERS. You don't have any clinical approach?

Dr. WHEDON. Yes, some of these centers in other diseases——

Mr. ROGERS. I am talking about arthritis.

Dr. WHEDON. In the one center we have in arthritis, there is a clinical component.

Mr. ROGERS. There should be.

Dr. WHEDON. There is.

Mr. ROGERS. Any center you establish should have a mix.

Dr. WHEDON. That is correct.

Mr. ROGERS. That is what we would provide in the bill.

Dr. WHEDON. Well, the bill calls for extension of broader training which would involve training of auxiliary personnel as well. That we do not do at the present time.

Mr. ROGERS. Is there a need?

Dr. WHEDON. I would agree there is a need, yes, sir.

Mr. ROGERS. What we have designed the legislation to do is try to begin to meet the needs, to overcome what we are not doing. That is the purpose of the legislation.

I won't pursue this any more. I think it is well established. We need to do more and we must do more if we are going to give any relief to people over the country here.

What about the nonrheumatologist physicians? I understand about 30 percent of them have never even been exposed to any type of formal training in rheumatoid diseases; would that be true?

Dr. WHEDON. I didn't understand, sir, the first words in your question, with regard to the type of individual.

Mr. ROGERS. Not the specialists.

Dr. WHEDON. General practitioners?

Mr. ROGERS. Yes.

Mr. CARTER. Mr. Chairman. I would have to object to that. I think as a part of every course of internal medicine each student certainly

has a basis of rheumatology or rheumatoid arthritis, and skeletal diseases throughout our country.

Mr. ROGERS. I won't pursue that. I understand that Dr. Shulman can give us comment on that perhaps.

Dr. WHEDON. I think we would all agree, and I believe Dr. Carter would as well, that instruction and training in this group of diseases surely ought to be better than it is.

Mr. ROGERS. How many program project grants is NIAMDD supporting outside the Institute for arthritis?

Dr. WHEDON. We are supporting one arthritis center at the Robert Breck Brigham Hospital in Boston and 10 program project grants located at University of Alabama, New York University, Boston University, Pritzker School of Medicine, Chicago, Boston Childrens Hospital, Massachusetts General Hospital (3), University of California at Los Angeles.

Mr. ROGERS. If arthritis legislation were to be enacted, which division of HEW is most appropriate to establish and operate or contract ont an arthritis data bank?

Dr. WHEDON. This type of work is the responsibility of the Center for Disease Control in Atlanta.

Mr. ROGERS. Which division of HEW is most appropriate to conduct and contract out early detection and screening demonstration projects and population studies for arthritis?

Dr. WHEDON. Similarly, the Center for Disease Control has been doing this type of work in infections diseases and nutrition. Earlier this year, in the National Diabetes Research and Education Act the authority in the Center for Disease Control for this work was further expanded.

Mr. ROGERS. Thank you.

Mr. CARTER. Mr. Chairman, we were talking about different medicines used in the treatment of rheumatoid arthritis and I believe they mentioned gold salts principally and cortisone also.

With this treatment do you get any remissions?

Dr. SIMMONS. Yes, we do.

Mr. CARTER. You do if osteoarthritic?

Dr. SIMMONS. They are spontaneous remissions. It is hard to know which is which.

Mr. CARTER. Have you really seen spontaneous remissions?

Dr. SIMMONS. Yes, I have.

Mr. CARTER. With what medicines have you seen remissions?

Dr. SIMMONS. As I said, we have seen remission.

Mr. CARTER. Other than spontaneous?

Dr. SIMMONS. It is difficult to know, as you know, when somebody is on therapy, when they have had remission from that or spontaneous.

Mr. CARTER. Thank you, Mr. Chairman.

Mr. ROGERS. Thank you so much. We appreciate your presence here today. We would be grateful to you if you would supply those items for the record.

Thank you.

Next we have a distinguished panel, and if those who are to be in the panel would be at the table, we will provide more chairs if you need them.

We have before us the chairman of the Board of Arthritis Foundation. Charles Harding will act as panel chief.

Mr. Harding.

STATEMENTS OF CHARLES B. HARDING, CHAIRMAN, BOARD OF DIRECTORS, THE ARTHRITIS FOUNDATION; DR. LAWRENCE SHULMAN, PRESIDENT, AMERICAN RHEUMATISM ASSOCIATION SECTION, THE ARTHRITIS FOUNDATION; DR. EPHRAIM P. ENGLEMAN, CLINICAL PROFESSOR OF MEDICINE AND HEAD RHEUMATIC DISEASE GROUP, UNIVERSITY OF CALIFORNIA SCHOOL OF MEDICINE, SAN FRANCISCO; DR. DAVID S. HOWELL, PROFESSOR OF MEDICINE AND CHIEF, ARTHRITIS DIVISION, UNIVERSITY OF MIAMI (FLA.) SCHOOL OF MEDICINE, AND VETERANS ADMINISTRATION HOSPITAL (MIAMI); DR. CARL M. PEARSON, PROFESSOR OF MEDICINE, AND DIRECTOR, DIVISION OF RHEUMATOLOGY, UNIVERSITY OF CALIFORNIA AT LOS ANGELES SCHOOL OF MEDICINE; DR. WILLIAM F. DONALDSON, FIRST VICE PRESIDENT AND PRESIDENT ELECT, AMERICAN ACADEMY OF ORTHOPEDIC SURGEONS; DR. HARLAN C. AMSTUTZ, IN BEHALF OF AMERICAN ACADEMY OF ORTHOPEDIC SURGEONS; DR. CLEMENT B. SLEDGE, IN BEHALF OF AMERICAN ACADEMY OF ORTHOPEDIC SURGEONS; DR. EVELYN HESS, MEMBER, EXECUTIVE COMMITTEE AND CHAIRMAN, COMPUTER COMMITTEE, AMERICAN RHEUMATISM ASSOCIATION; AND JANICE MAYNARD, REPRESENTING THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION

STATEMENT OF CHARLES B. HARDING

Mr. HARDING. Mr. Chairman, with your permission, I would like to make a brief statement, then introduce the panel, and turn the discussion over to them.

Mr. Chairman and members of the House Subcommittee on Public Health and Environment, my name is Charles B. Harding. I am chairman of the board of directors of The Arthritis Foundation, a national voluntary health agency with national offices in New York City, and 73 chapters located in 49 States.

I am a member of the advisory board of Smith Barney & Co., investment bankers. I was privileged to have been a senior partner of the firm for 20 years and, just before my retirement, to have served as president and chairman of the board. I am also director and chairman of the Cerro Corp.

I mention these relationships not to impress this prestigious committee, but simply to preface certain remarks concerning the economic facts of arthritis which the public, and in particular the Government, seem to have overlooked.

Arthritis, the Nation's No. 1 crippling disease—second only to heart disease in causing disability—affects 20.3 million Americans and one out of every four families.

The cost of arthritis to the Nation in premature deaths, loss of economic productivity, loss of tax revenues because wage earners become disabled, disability insurance payments, loss of homemaker services, medical expenses, and quackery, originally calculated at $3.6 billion annually in 1966, this figure has risen to over $9.2 billion per year as of 1972, or an increase of nearly $1 billion per year. Updating this, the estimate for 1975 would be a minimum of $12 billion.

Eight years ago the Department of Health, Education, and Welfare conducted a cost/benefits analysis of a proposed arthritis centers program, not too dissimilar from that proposed in this committee's bill, H.R. 14181. It concluded that for every Federal dollar expended on the project, $41 would be returned to the national medical costs and increased contributions by skilled Americans to this Nation's economic future. As an investment banker, I find it extraordinary that the Government has failed to take initiatives in this direction until now, in view of the economic benefits to be derived from such a program.

In support of these estimates, Mr. Chairman, I submit detailed study made by Dr. Sisk and David Shobe of the Arthritis Foundation [see p. 88.]

Since 1950, when the National Institute of Arthritis, Metabolism, and Digestive Diseases was established—thanks largely to major effort by the Arthritis Foundation which had been born 2 years earlier—less than $118 million has been expended on extramural research grants in arthritis to individual investigators around the country.

In 24 years, $118 million, or less than $5 million a year for support of arthritis research—this for a disease which seriously disables nearly 3.5 million Americans. Parenthetically, only some 100,000 fewer than are disabled by heart disease.

The arthritis centers about which we are talking today would be a major advance in arthritis. In the early sixties, six medical schools were aided by the national foundation, or March of Dimes, at a level of about $50,000 to $60,000 each to try to create clinical arthritis research teams. In 1965, when the Arthritis Foundation took over the funding of these teams, the level of aid to the units fell from $60,000 per unit to about $30,000. It has declined more in subsequent years despite the doubling of public support of arthritis research because the foundation's Medical Administrative Committee has chosen to aid more units—42 as of this date. The result is a lower amount per unit—this year it is only $12,000—representing a total commitment of $500,000. To this is added several hundred thousands of dollars by the foundation's 73 chapters in direct support of certain of these and other units. So you see, arthritis insofar as institutional grants are concerned, is not doing well at all.

In regard to the training of arthritis researchers, because of recent reductions in Federal support to prospective medical researchers, the foundation is now aiding more postdoctoral fellows in rheumatology than is the Arthritis Institute. We do not mind being in the forefront. We were there once before when we started our fellowship program in 1951, a year before one was initiated by NIAMDD. It seems such a waste, however, to have had the Government develop a certain forward momentum in arthritis research, only to have this momentum stilled by budgetary neglect.

It has been proven, time and again, by the fight against smallpox, tuberculosis, infantile paralysis, and other diseases which can now be controlled through vaccination or other measures, that the increased health of a nation achieved by eradicating a costly disease can immeasurably add to our productivity, and to our enjoyment of living at any and every age.

The Arthritis Foundation unreservedly endorses the goals of H.R. 14181 and the measures it proposes to achieve these ends. We consider it to be a major and wholly justified acceptance by the public sector of joint responsibility with the private sector—as represented by the efforts of the Arthritis Foundation.

We thank you, Mr. Chairman and members, for this opportunity to testify today on behalf of legislation, and we reiterate our gratitude to you and to other Members of the House for introducing and supporting it.

[The study on costs of arthritis, referred to, follows:]

COST OF ARTHRITIS IN THE UNITED STATES

Charles W. Sisk, M.D., Director, Department of Medical and Scientific Affairs, The Arthritis Foundation and David Shobe, Director of Government and Community Affairs, The Arthritis Foundation

Health statistics are analogous to the stock market—you never have either sufficiently accurate or enough data to allow you to reach any firm conclusions. This is particularly true when attempting to estimate economic losses attributable to the rheumatic diseases. Reasonable prevalence estimates, as you have heard earlier in this Symposium, are in themselves difficult to establish with any reasonable degree of confidence. How then can one compile accurate economic data on some 80–100 diagnostic entities for which very imprecise prevalence estimates exist for the large majority? Even with a centralized data bank and universal reporting of illness it still represents a difficult task. Without such facilities it constitutes a virtually impossible task. Notwithstanding all the probems implicit in assessing the economic impact of the rheumatic diseases we have nevertheless accepted the challenge. Because of the many unknowns involved in developing these estimates, we note the questionable assumptions one must adopt and attempt to determine whether they are likely to represent high or low projections of the actual magnitude of the economic burden imposed by the rheumatic diseases.

Most of the data we present has been taken from the National Health Interview Survey of 1969–1970. This Survey was conducted by the National Center for Health Statistics as a part of the 1970 U.S. Census. A random sample of 42,000 households representing 135,000 noninstitutionalized civilians were interviewed by trained census personnel. The questionnaire used was developed by the National Center in collaboration with the Chronic Disease Control Program of the Public Health Service. Although there is no published report on the accuracy and reliability of the questionnaire, I'm assuming it adequate to extrapolate cost estimates for arthritis. Suffice to say that its accuracy seems adequately documented from pre-survey testing in terms of the ability to detect the majority of actual rheumatic complaints. Comparable to most interview data to obtain point prevalence data, however, it probably underestimates the true prevalence of these complaints. Finally, one last note of caution needs emphasis. The questionnaire was totally inadequate for obtaining prevalence estimates of specific diseases. Thus, all data which we present cannot be broken down in terms of the economic costs attributable to rheumatoid arthritis, osteoarthritis or other rheumatic diagnoses. Instead, each prevalence figure represents the combined prevalence of both rheumatic complaints and specific rheumatic diagnosis as stated by the interviewee. In other words, persons stating they had a particular form of arthritis were included in the prevalence figures irrespective of whether or not they had any specific rheumatic complaints. Similarly if an individual had a rheumatic complaint and denied having arthritis, he would also be included in the prevalence figures. The diagnostic rubrics used for inclusion were taken from the 8th Re-

vision of The International Statistical Classification of Diseases (See Footnote—Table 1).

Table I shows these prevalence estimates for the United States. Note that they exclude lumbago and torticollis and as a consequence, probably under-represent the prevalence of symptoms due to discogenic or vertebrogenic disease—known major contributors to the total body of rheumatic complaints. Still another indication that these figures may represent under-estimates is the 75,000 projected cases in children under 17 years of age. Reputable pediatric rheumatologists claim that a minimum estimate for JRA alone in the United States approximates 150,000 cases. On the other hand, the estimates for older age groups do not seem out of line with much of the data derived from epidemiologic studies.

Using these prevalence figures as a base, what are the projected economic losses from arthritis? In presenting this we will first discuss indirect costs and then direct costs. Under direct costs we include loss of productivity either due to unemployment or workdays lost from disability, loss of income taxes from unearned income, loss of wages due to premature death, disability insurance, aid to the disabled and veterans compensation. Direct costs consist of the remaining items listed in Table VII.

Table II lists projected wages lost by males due to unemployment from disability.[1] Table III consists of the same data for females. The expected wages per person were obtained from age-sex specific average incomes provided by the U.S. Department of Labor.[2] These values seem particularly modest in this day and age of galloping inflation. The data for disability in the first column was also taken from the NHIS. In comparing Tables II and III note particularly the great discrepancy between lost wages for males and females. As more women join the labor force—recent information indicates they are doing this—the total wage losses for this group will undoubtedly rise disproportionately and tend to further magnify the actual economic impact of arthritis.

In Table IV the data for both sexes are combined. As you see, the total dollar loss resulting from lost productivity is the enormous sum of 2.981 billion dollars. Referring again to Table IX one is impressed that this figure constitutes by far the major component of all cost factors. Interestingly, this factor has usually been omitted in previous reports estimating the cost of arthritis.

Using the same reference sources as before, the earning lost due to workdays lost are presented in Table V. The total workdays lost, approximately 15 million, seems particularly small in comparison with statistics from Great Britain.[3] Nevertheless we prefer to adopt this figure in order to remain on the conservative side in our estimates. Notable in these data is that about one in 6 persons with rheumatic complaints suffer from varying degrees of activity limitation and that arthritis largely takes its toll, as might be expected, in earnings lost in the 45–64 year age group.

Certainly any reasonable estimate of economic losses due to arthritis must include an assessment of disability in women who are not considered a part of the labor force (Table VI). By this we refer specifically to homemakers. For this group the Department of Labor projects the average homemaker to be worth $3,770 in 1969. Multiplying this figure by the estimated number of disabled homemakers,[4] one obtains an annual loss of $974,000,000 theoretically representing the total dollar equivalent for homemakers services. I find these data of interest primarily because they do not seem to reflect the devastating effect of RA in females of the 45–64 year age group. Empirically, we must conclude that rheumatoid patients of this age generally under-report their degree of disability.

Another cost factor that needs to be included in our estimates is the loss of productivity resulting from premature death (Table VII). The value entered here is based on 4,908 persons who reputedly died from rheumatic diseases in 1969. This figure does not include rheumatic heart disease. It is derived from Social Security data[5] and computed on the basis of anticipated, aggregated age-sex specific earnings as described by Rice.[6] If we compare this mortality figure with that reported by Wood[3] in Great Britain, it is only half as great when extrapolated to the same population size. Thus there is good reason to believe that this estimate may also be on the conservative side. We assume the difference between the U.S. and Britain simply represents different coding techniques for cause of death in the two countries.

Having estimated a dollar equivalent for lost productivity due to the rheumatic diseases it is no problem to estimate the loss of income tax revenues resulting from this reduced productivity. This amounts to $773,000,000. An estimate of all disability payments are included as items 5, 6 and 14 (Table VI). Disregarding

See footnote on pp. 90–91.

problems with diagnostic misclassification, these expenditures are, of course, well documented for both veterans and the civilian population [7-8]. Summarising these values gives a total estimate of $840,000,000 for both federal and non-federal disability payments.

Now we mention briefly the direct costs of arthritis. The data used in obtaining these estimates were also primarily obtained from the NHIS. As you note, hospitalization costs amount to $854,000,000. These costs were incurred by 255,000 patients admitted one or more times to U.S. hospitals in 1969 [9]. This group of patient constituted 4.3% of all hospital discharges in that year. This figure is probably reasonably accurate if one only counts those arthritics admitted to hospitals as a direct consequence of rheumatic complaints. We doubt that it fairly deals with the problem of comorbidity which plays a major role of the overall health problem imposed by the rheumatic diseases. As an example, we do not believe this estimate would include a rheumatoid patient who—because of severe osteoporosis sustained a femoral fracture and is admitted to the hospital for treatment of the fracture.

In terms of outpatients costs, the NHIS recorded 32.9 million physician visits by patients with rheumatic complaints in 1969 [10]. This accounted for 4.2% of all office visits and amounted to $493,500,000 in out-of-pocket and third party expenditures excluding drugs. Non-physician services, including physiotherapy, other allied health professional services and incidental costs contributed expenses estimated at $50,000,000.

The remaining cost items are very difficult to estimate with any degree of accuracy. The figures for prescribed and non-prescribed drugs was taken from the NCHS survey of 1965 [11] on a national probability sample comparable to the one for the arthritis NHIS. We can place little reliance in these values because of the problems inherent in obtaining satisfactory interview data regarding the taking of medications. It seems reasonable to assume, however, that arthritics consume approximately 10–11% of all drug sales in the U.S. This amounts to approximately $600,000,000 in prescription drugs and $500,000,000 in non-prescription drugs.

No good data exists for expenditures on quackery. The only information available of this kind derives from a study done by the Arthritis Foundation in 1960.[12] In this survey of a non-random sample of 1,000 arthritics, cost estimates were extrapolated as $435,000,000, for the U.S. This figure was considered conservative by 1960 standards.

The last cost factor, item 16, in Table VII, constitutes both federal and private support of all research and training in arthritis. Our primary reason for including this figure is to contrast it with our total economic liability for the rheumatic diseases. Certainly it is miniscule in comparison and would seem to leave little doubt that our country needs to invest more in its leading cause of disability.

Throughout this exercise we have attempted to project conservative estimates of our economic liability for arthritis in the U.S. Thus, we consider the total cost figure of over $9,000,000,000 to be a minimal projection of the actual cost. Undoubtedly if we were to prorate our estimates upward in accordance to the change in the cost of living index between 1969 and the present, these figures would be increased at least 30%, thereby raising the total cost to approximately $12,000,000,000.

FOOTNOTES

(1) Unpublished data from the National Center for Health Statistics—Division of Health Interview Statistics, 1973.

(2) Employment and Unemployment in 1969. Special Labor Force Report No. 116, U.S. Department of Labor, Bureau of Labor Statistics.

(3) Wood, PHN, Benn RT, Statistical appendix, Ann Rheum Dis 31: 72–77, 1972.

(4) Employment Status of Uninstitutionalized Population, Special Labor Force Report 143, U.S. Department of Labor, Bureau of Labor Statistics, 1971.

(5) Vital Statistics of the U.S. Mortality, Part A, vol. 2, 1963.

(6) Rice DP, Estimating the Cost of Illness, DHEW Pub. No. 947–6 Health Economics Series No. 6, 1966.

(7) Findings of the 1970 APTD Study Part I, Demographic and Program Characteristics DHEW Pub. No. SRS 73–03853, National Center for Social Statistics, Report APTD–1, 1970.

(8) Personal communications with Scott Mason, Veterans Administration Central Office, Washington D.C., 1973.

(9) Personal communications Clint Burnham, National Center for Health Statistics, 1973.
(10) Ibid.
(11) Prescription and Non-Prescription Drugs Vital and Health Statistics Series 10, No. 39, 1965.
(12) Walrad R; The Misrepresentation of Arthritis Drugs and Devices in the U.S.

TABLE I.—PREVALENCE ESTIMATES OF ARTHRITIS AND REHEUMATIC CONDITIONS BY AGE AND SEX IN THE U.S.

AGE	Total	Male	Female
Under 17	75,000	[1] 36,000	[1] 39,000
17 to 44	3,315,000	1,176,000	2,139,000
45 to 64	9,184,000	3,362,000	5,822,000
65 and over	7,656,000	2,614,000	5,042,000
All ages	20,230,000	7,188,000	13,042,000

[1] Estimated.

Note: ICOA - 710-716, 717.1, 717.9, 718, 726, 730-733, 735, 738, X70-X79, N800-N839. Includes acute pyogenic, non-pyogenic and traumatic arthritis, adult and juvenile rehumatoid arthritis, spondylitis, osteoarthritis and allied conditions; polyomyositis, dermatomyesitis and fibrositis. Excludes lumbago and torticollis.

Source: Unpublished data from the 1969-70 Health Interview survey. Unpublished data from the National Center for Health Statistics—Division of Health Interview Statistics, 1973.

TABLE II.—ANNUAL LOSS OF WAGES DUE TO INABILITY TO BE EMPLOYED BECAUSE OF ARTHRITIS AND RHEUMATIC CONDITIONS IN THE UNITED STATES,1969-70

Ages	Unable to carry on usual activity	Males estimated to be working if not disabled	Expected wages per person	Total estimated lost wages (millions of dollars)
17 to 44	24,000	22,092	$9,426	208.2
45 to 64	197,000	175,330	10,242	1,797.3
65 and over	359,000	97,648	5,927	578.8
All ages	580,000	295,070		2,584.3

Source: Health Interview Survey: Unpublished data from the National Center for Health Statistics—Division of Health Interview Statistics, 1973 and U.S. Department of Labor, Bureau of Labor Statistics. Employment and Unemployment 1969. Special Labor Force Report No. 116, U.S. Department of Labor, Bureau of Labor Statistics.

TABLE III.—ANNUAL LOSS OF WAGES DUE TO INABILITY TO BE EMPLOYED BECAUSE OF ARTHRITIS AND RHEUMATIC CONDITIONS IN THE UNITED STATES,1969-70

Ages	Unable to carry on usual activity	Females estimated to be working if not disabled	Expected wages per person	Total estimated lost wages (millions of dollars)
17 to 44	12,000	5,952	$5,690	33.9
45 to 64	85,000	44,880	5,604	251.5
65 and over	225,000	25,245	4,418	111.5
All ages	352,000	76,077		396.9

TABLE IV.—ANNUAL LOSS OF WAGES DUE TO INABILITY TO BE EMPLOYED BECAUSE OF ARTHRITIS AND RHEUMATIC CONDITIONS IN THE UNITED STATES, 1969-70

Ages	Unable to carry on usual activity	Both sexes estimated to be working if not disabled	Total[1] estimated lost wages (millions of dollars)
17 to 44	36,000	28,044	242.1
45 to 64	281,000	220,210	2,048.8
65 and over	615,000	122,993	690.3
All ages	932,000	371,147	2,981.2

TABLE V.—ANNUAL WORKOAYS LOST ANO EARNINGS LDST DUE TO DISABILITY CAUSED BY ARTHRITIS AND RHEUMATIC CONDITIDNS, BDTH SEXES, 1969-70

Age	Prevalence (millions)	Persons with activity limitation due to arthritis (thousands)	Workdays lost (thousands)	Earnings lost (millions of dollars)
17 to 44	3.32	346	2,786	98.6
45 to 64	9.18	1,355	10,341	391.3
65 and over	7.66	1,763	1,771	41.0
All ages	20.16	3,464	14,898	530.9

TABLE VI.—ANNUAL LOSS OF HOMEMAKERS SERVICES DUE TD ARTHRITIS ANO RHEUMATIC CONDITIONS, 1969-70

Age	Females unable to carry out usual activities due to arthritis	Not in labor force (thousands)	Estimated to be homemakers (thousands)
17 to 44	12	6.0	5.3
45 to 64	85	40.1	39.2
65 and over	255	229.8	213.9
Total	352	275.9	258.4

Note: Estimated cost of homemaker services per homemaker, $3,770; total homemaker loss $974,051,000.

TABLE VII—*The annual cost of arthritis, 1969*

	(*Millions of dollars*)
(1) Wages iost due to inabiiity to be employed through disabiiity	$2,981.2
(2) Wages iost due to activity iimitations	530.9
(3) Homemakers serviees iost	974.1
(4) Loss to Federal, State, and Local Governments of income taxes	772.6
(5) Disability Insurance Payments	316.0
(6) Aid to the permanently and totaiiy Disabled	132.0
(7) Hospitaiization	854.0
(8) Physieians Office Visits	493.5
(9) Amount spent on quackery produets (estimated)	435.0
(10) Amount spent on non-preseription drugs (estimated)	500.0
(11) Amount spent on preseription drugs (estimated)	600.0
(12) Earnings ioss due to premature death	194.0
(13) Otiier than Physician Services	50.0
(14) VA Compensation & Disabiiity	394.4
(15) Federai and Private programs for arthritis	26.0
Total	9,253.7

[The following letter was received for the record:]

THE ARTHRITIS FOUNDATION,
New York, N.Y., November 26, 1974.

Hon. PAUL G. ROGERS,
House of Representatives,
Washington, D.C.

DEAR MR. ROGERS: I want you to know how mueh I appreciate the time whieh you and your eommittee have given to the consideration of H.R. 14181.

After the Hearing, as is usually the ease, I thought of a coupie of remarks that I shouid have made but did not. These are that in over 50 years in the investment business, I have never seen an investment so attraetive that a doiiar invested had a potentiai return of $41.00. The Biii, which wouid provide $5 miiiion a year for researeh in arthritis, has this potentiality over a reasonable period of time.

There are few government expenditures which provide *any* return to the taxpayer and I know of none that have the potentiality of return that this one has.

It seems to me that it is not a matter of whether or not we can afford this annual expenditure but that we cannot afford not to make it.

Sincerely yours,

CHARLES B. HARDING,
Chairman, Board of Directors.

Mr. HARDING. I would now like to introduce the president of the American Rheumatism Association Section of the foundation, Dr. Lawrence Shulman, who will chair this panel of distinguished leaders in rheumatology and orthopedics.

Thank you very much, sir.

Mr. ROGERS. Thank you very much, Mr. Harding, for being here and for this excellent beginning statement for the work you have done in this field.

Dr. Shulman, we welcome you and distinguished members of your panel and you may proceed as you desire. For the benefit of the reporter, it might be well if we could have each identify so she will know.

STATEMENT OF DR. LAWRENCE E. SHULMAN

Dr. SHULMAN. Mr. Chairman and members of the House subcommittee, I would like to present my written testimony for the record, please.

Mr. ROGERS. Yes [see p. 97]. And any other witnesses in your panel who have written statements will be made part of the record in full without objection.

Dr. SHULMAN. Thank you, sir.

As you have heard, my name is Lawrence E. Shulman. I am director of the arthritis programs at the Johns Hopkins Medical School and Hospital in nearby Baltimore.

I have served on many committees of our professional society, the American Rheumatism Association, and have been chairman of its Program, Membership and Conferences Committees. I have also been on the Research Committee of the Arthritis Foundation, and for the past 2 years chairman of the Committee to Evaluate the Medical and Scientific Programs of the Arthritis Foundation.

This past April, I had the privilege of cochairing, with Dr. William Donaldson who will be testifying here today, a workshop on arthritis centers, held in Chicago, and we did communicate our findings on that with you.

As you have heard, I now have the privilege of serving as president of the American Rheumatism Association, which is our national professional society, consisting of some 2,400 physicians, surgeons, scientists, who have special interest and commitment to the arthritis field.

My colleagues who are with me and before you today are or have been officers of the American Rheumatism Association and the American Academy of Orthopedic Surgeons. For our patients and ourselves, we want to thank both you, Mr. Chairman, and Dr. Carter so very much for introducing this important legislation, the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974.

We also extend our gratitude to other congressmen for endorsement of H.R. 14181.

We support your act enthusiastically.

We are also grateful for the opportunity to testify before you today to discuss some of the developments, issues and problems in the rheumatic disease field.

The first is that the rheumatic diseases constitute a major public health problem in the United States. The 1969 national health survey, which was referred to on many occasions here, gave us some very important information. The answer to your previous question is, that there are no more data since 1969. Special attention was given to arthritis and cancer in that survey.

You are correct in saying that the prevalence of arthritis has increased. Over 10 years, the prevalence of arthritis increased from 6.4 to 10.3 percent of the population during that decade. It has been progressively increasing.

As you know, arthritis and related diseases constitute the greatest cause of chronic pain and disability in the Nation.

Very interesting figures are provided in an article by Kerr White in the Scientific American, which tells us that arthritis is the leading cause of persons with limited activity in the United States and the third leading cause for people staying in bed. People with arthritis are not just staying home; many have to go to bed with these diseases.

Also, arthritis is the second leading cause of patients visiting doctors. Therefore arthritis is a big problem.

You have already alluded to the fact that arthritis can affect all ages.

Almost half the people affected by arthritis are in the middle age group, 45 to 64 years of age, a time in life when it is difficult to accommodate to changes that must be made.

Yet in 1969 some 1.2 million people, according to that survey, had to change their jobs because of arthritis, and 1.4 million people had reduced income because of arthritis.

The second point which I would like to underscore is that rheumatic diseases now comprise a major and rapidly expanding field of medicine. It is not just one disease; it includes all forms of arthritis, which specifically means inflammation of joints, and rheumatic disease, a broader term indicating disease in joints and/or other elements of the musculoskeletal system. Some rheumatic diseases are confined to joints; others are systemic diseases.

Ten years ago a committee of the American Rheumatism Association constructed a classification of rheumatic disease, and at that time there were 84 different rheumatic disorders that could be grouped into 13 different categories.

This includes many diseases that cripple young people. These would be ankylosing spondylitis, psoriatic arthritis, Reiter's syndrome and juvenile rheumatoid arthritis, which Dr. Carter referred to.

We also have diseases with high mortality. We don't have good data on their frequency. They include diseases such as systemic lupus or scleroderma. These are diseases that affect young people—can kill them, or disable them tremendously.

We also have new diseases. Since 10 years ago when we had 84 different rheumatic disorders classified, we would now have almost 100, if we were to reclassify at the moment.

Concerning research, Dr. David Howell and Dr. Carl Pearson will be discussing that with you in a bit.

I should like to indicate that we have some research successes already. The gout story is a huge success. There are 1 million people with gout in the United States. We now know how this disease comes about, and we now have methods for completely managing this disorder.

The mission here is to educate both the physician and the public to obtaining the right care.

We have exciting and promising investigation in the field of rheumatoid arthritis and systemic lupus. Dr. Pearson will be discussing that.

We have a feeling that very significant discoveries will appear in the near future in these areas.

In others, such as osteoarthritis, far too little research activity is going on.

We have new leads in terms of the young crippling diseases of young men, such as spondylitis and other forms of the disease. In terms of the discovery of a specific tissue typing factor, HL–A W27, in 1973, it was found in 95 percent of patients had spondylitis, as compared to 4 or 5 percent of the general population. A new method to uncover patients with this disease is provided.

And the tremendous progress in orthopedic surgery has been very impressive. Much more support is needed. As rheumatologists, we would like to strongly support that section of your act which establishes and intramural orthopedic surgery program.

My intent here is just to share with you the excitement and optimism that my colleagues and I share, really have, in terms of potential and meaningful discoveries in this field.

New tools have been developed, and we need to develop more tools, by which screening, detection, and control programs might be produced and executed. Uric acid screening for the general population, as you would carry out diabetes screening in the general population, would be very useful. Rheumatoid factor screening for rheumatoid arthritis and other diseases, antinuclear antibodies, immunologic factors, this new discovery of (HL–A) W27 in the spinal diseases would also lend themselves to control programs.

As you have heard, a productive momentum has been created and it is now in danger.

Research support, as you have so well delineated, has remained static for years in dollar amounts.

Now, with inflation, this means a sharp reduction in actual meaningful research. So, if we do make a comparison with cardiology, as Dr. Carter did, the notion of having $14 million for arthritis, and $300 million for heart disease is certainly grossly imbalanced.

The third major point is that we have a critical manpower shortage in rheumatology. I have here, and would like to submit for the record, this "Professional Manpower in Rheumatology" report that was prepared by the management consulting firm of Cresap, McCormick and Paget, in 1972. This was done in conjunction with the Manpower Study Committee of the American Rheumatism Association.

In terms of the number of rheumatologists in the United States, the figure that is often given is 2,000—in fact, sir, it is less than that.

This represents the membership of the ARA as 2,000–2,400. But this society includes research scientists, orthopedic surgeons, and others, who spend only a minority of their professional time caring for arthritis patients.

We would estimate, I have done this with my colleagues here, that rheumatologists who are really specializing in this area and are available for patient care, would number a little under 1,000.

Therefore, this means that there are 1,000 physicians to serve 20 million people with arthritis in the United States.

Now, this manpower deficit is due to past indifference and due to cutbacks in the training grant support. It should be absolutely emphasized that a momentum had been created by the training grant mechanism, we went from four training programs in 1955 all the way up to a high of 43 in 1962, and we have been going downhill ever since.

We heard a figure from Dr. Whedon of 24 training grant programs next year, the year after that there is going to be virtually nothing in terms of significant training program support.

With respect to our medical schools, your figure is generous. There are 40 of our 115 medical schools that have no rheumatology programs at all.

There are other medical schools that are grossly undermanned with respect to rheumatology programs to carry out the basic and clinical teaching, that this enlarging field needs.

New schools are finding it hard to find trained rheumatologists.

In addition there is a gross maldistribution in manpower. For example, some States have no rheumatologists. We have a figure that there are 16 States in the Nation that have an average of three rheumatologists per State. That means the whole State of Nevada has none, South Dakota has none, and other States, which are populous, have very few rheumatologists.

Therefore, it is no wonder that there is a gap in the knowledge of rheumatic disease among general physicians. To clarify the question which you were asking about a 1972 survey funded by the consultants, that indicated that 70 percent of nonrheumatologist physicians have had no formal training in rheumatology.

The 1969 health survey showed that of the 20 million people with arthritis, 12 million were not under any care for their arthritis; a very impressive figure.

Mr. Rogers. 12 million?

Dr. Shulman. Yes. Moreover, the CMP survey showed a need for a 630-percent increase in the number of rheumatologists. The actual number is 9,300 additional rheumatologists that would be required by 1981.

They were going on the basis of 2,000 now. If we take my figure of 1,000 practicing rheumatologists, we would then need a ninefold increase in the number of rheumatologists by the next decade. The need for increased training is obvious.

This act of yours will make giant strides in correcting that gap.

For these and other reasons, your provision on page 17, line 9 of your act, of $3, $4 and $5 million in successive years for those medical schools that do not have any or only minimal staffing, to train the general physician, is absolutely mandatory.

That is the way to get knowledge out into the community. If you want to give good primary care, that is the way to do it. We must train every single graduating student in the basic knowledge of care for the rheumatic diseases.

There are gaps in research scientists; only 27 schools, I would estimate, are staffed nominally in rheumatology research.

Lastly, the manpower shortage in the allied health professions, as you will hear about, is even more critical.

I now turn the discussion over to Dr. Engleman, who will discuss the critical needs, functional and operational aspects of the proposed centers.

[Testimony resumes on p. 145.]

[Dr. Shulman's prepared statement and "Professional Manpower in Rheumatology," study follows:]

STATEMENT OF DR. LAWRENCE SHULMAN, PRESIDENT AMERICAN RHEUMATISM ASSOCIATION SECTION, THE ARTHRITIS FOUNDATION

Mr. Chairman; Members of the House Public Health and Environment Subcommittee: My name is Lawrence E. Shulman, M.D., Ph.D. I am Director of the Connective Tissue Division (Rheumatology Programs) at The Johns Hopkins University School of Medicine in nearby Baltimore. I am well acquainted with the vital activities of the National Institute of Arthritis, Metabolism and Digestive Diseases, having served on the Arthritis Research Training Grant Committee as both member and chairman in the 1960s. Moreover, for the past three years I have been Consultant for Rheumatic Diseases for the Clinical Center of the NIH. For five years I was the recipient of the Senior Investigator Award of The Arthritis Foundation. I have served on many committees of our professional society, The American Rheumatism Association; and have been chairman of its Program, Membership and Conferences committees. I have also been on the Research Committee of The Arthritis Foundation; and for the past two years Chairman of the Committee to Evaluate the Medical (and Scientific) Programs of The Arthritis Foundation. Moreover, just last April I had the privilege of co-chairing, with Dr. William Donaldson who will be testifying here today, a Workshop on Arthritis Center, sponsored by the NIAMDD, American Academy of Orthopedic Surgeons, and The Arthritis Foundation, in Chicago. I have also been chairman of the Scientific Group on The Diffuse Connective Tissue Diseases of the World Health Organization in Geneva. I am a Fellow of The American College of Physicians, and a member of several scientific societies.

I appreciate very much the opportunity to testify before you today, and to discuss with you some of the developments, issues and problems in the rheumatic disease field. I have the privilege of serving this year as President of The American Rheumatism Association, the national professional medical society in the field, consisting of over 2,400 physicians, surgeons and scientists who specialize in arthritis and related musculoskeletal diseases. It was founded in 1935, and is now a Section of The Arthritis Foundation (AF), the sole voluntary agency in this field. In 1965, a new professional section—the Allied Health Professionals (AHP) section was formed in the AF; its members are physical therapists, occupational therapists, social service workers, psychologists and others with special interests in the rheumatic diseases.

Rheumatic diseases constitute a major public health program. According to the 1969 National Health Interview Survey, more than 20,000,000 people in the United States reported that they were suffering from one or another of the rheumatic diseases in that year. Also, the overall prevalence of the rheumatic diseases had increased progressively in the previous decade from 6.4 to 10.3 percent. Almost half of the people with arthritis are in the 45–64 year age group, a time in life when their incomes tend to become fixed, and their abilities to accommodate to the consequences of disabling illness become constricted. Patients with arthritis suffer not only pain, but also restriction of their activities; and some become confined to bed. The 1969 survey estimated that 1,200,000 people had to change their jobs because of arthritis, and an even greater number of people reported a decrease in income attributed to their arthritis.

According to a cost-benefit analysis prepared two years ago by a group of experts and consultants for the Arthritis Foundation, the total cost to the United

States economy, including health services and lost work productivity, from arthritis and related diseases amounts to more than 9 billion dollars each year.

The public's view of arthritis is an erroneously restricted one. It thinks of arthritis as one, or perhaps two, diseases affecting the elderly. If severe enough, it may cause crippling and disability. It gets worse in rainy weather. The cause is unknown. There is no cure. The person with early arthritis thinks to himself: "There is little use in going to the doctor, because after all, he will only give me aspirin, and I can get stronger medicine at the corner drug store with the advice of my television set."

The facts are that prior to twenty years ago the study of rheumatic diseases was grossly neglected. It is now a rapidly expanding field of medicine. The first breakthroughs came in the late 1940s with the discoveries of new diagnostic tests for rheumatoid arthritis and systemic lupus erythematosus, and of a dramatic new treatment for rheumatoid arthritis, rheumatic fever, systemic lupus and other diseases in the form of cortisone, for which the late Dr. Philip Hench, a former president of our American Rheumatism Association, won a Nobel Prize. Since then, many other important new agents have been discovered.

The real growth in this field emerged in the 1950s, with the programs of the National Institutes of Health and The Arthritis Foundation. The NIH programs, more specifically those of the National Institute of Arthritis and Metabolic Diseases, consist of Graduate Research Training Grants to some of our medical schools, and support for biomedical research. The research programs include both the intramural programs at the Clinical Center of The N.I.H. in Bethesda and the extramural research project grants to our universities on a competitive basis of peer review. These programs have supported and produced most of the new leaders of rheumatology in the nation today.

The Arthritis Foundation, which has had progressive financial growth, but still is only moderately endowed, now spends $2,200,000 on its medical programs. These include professional education, public education, advanced research fellowships, and support for clinical centers. These centers are supported extremely suboptimally in relation to the needs and their potential.

With these developments and activities, the field of rheumatic diseases began to flower in many ways. The rheumatic diseases now comprise a major field of medicine (not one or two diseases). Included within it are all forms of "arthritis," which in strict professional terms means inflammation of joints, although it is often used more generally to indicate any joint disorder. "Rheumatic disease," "rheumatism," and "connective tissue disease" are broader terms, indicating disease in joints and/or other elements of the musculoskeletal system: some rheumatic diseases are confined to joints; others are systemic diseases. Ten years ago, a committee of The American Rheumatism Association constructed and published a classification of rheumatic diseases; it contained 84 different rheumatic disorders, grouped into 13 categories. The list includes many diseases that may seriously cripple young people—ankylosing spondylitis, psoriatic arthritis, Reiter's syndrome and juvenile rheumatoid arthritis. It includes others with a high mortality, such as systemic lupus or scleroderma; these also mostly affect young people.

An example of success of arthritis research is gout. From the brilliant research of Seegmiller, McCarty, Gutman and others, virtually all the major questions concerning the cause and cure of this ancient and honorable disease have been answered. Several basic metabolic enzyme defects have been identified. The intimate details of the acute attack of painful arthritis are now well understood. Drugs have been developed and are now available to treat the acute arthritis, prevent further attacks of arthritis and joint destruction, rid the body of excess urate, bring the uric acid level in the blood back to normal, and prevent kidney stones. What is now needed is enhanced and improved medical and patient education, and more physicians capable of diagnosing and treating the 350,000 people with gout in the United States. The disease is now manageable.

Similarly high levels of research activity (and productivity) are now going on in the other major areas of our concern. There are exciting and promising rheumatologic investigations in immunology, immunogenetics and virology that make many of us believe realistically that the etiology of such diseases as rheumatoid arthritis or systemic lupus may be known in the near future. Moreover, we have several experimental animal models of rheumatoid arthritis or systemic lupus which suggest important roles for infectious agents and immunologic hyperreactivity under genetic control. In addition, basic research in rheumatology has contributed greatly to other fields, such as cancer research, and vice-versa.

Osteoarthritis is an important degenerative disorder which affects some 9 million people in the nation. Although there are now promising research tools with which to study this disease, the number of research grants and laboratories devoted to this problem is pitifully small, perhaps only 10–20 in the entire nation: this must be corrected.

Juvenile arthritis, which affects at least 250,000 children, was previously considered to be one disease. Recent research has shown clearly that there are several arthritic diseases in children; one of these, for example, is associated with antinuclear antibodies and chronic inflammation of the eyes. The opportunity for early detection and the prevention of blindness by early treatment is apparent.

Much of the research effort in rheumatology concerns the pathogenesis and treatment of the "collagen diseases" or diffuse connective tissue diseases, a series of potentially serious, at times life-threatening, diseases which affect many organs of the body, most often in young people. Systemic lupus erythematosus (SLE) is an immunologic disorder, with lesions in joints, skin, kidney, brain and other organs, mostly in young women. A major advance has been the clear demonstration that immune complexes cause tissue injury; i.e., DNA-antiDNA antibody complexes are responsible for the kidney lesions of SLE; other complexes have been identified. Recent investigations have shown that cell-mediated immunity is also disturbed in SLE. High levels of antibodies to several viruses have been found in SLE; and tuboreticular (virus-like) structures have been detected in the lesions of SLE by electron microscopy. Lupus tends to run in families, and the recent demonstration of a preponderance of certain histocompatibility antigens in patients with SLE seems particularly significant. Fortunately, experimental models of SLE are available in certain inbred strains (NZB/NZW) of New Zealand mice, which spontaneously develop a disease that mimics human SLE, and in certain dogs studied in Boston. Research data obtained from the NZB/NZW mouse model have generated new concepts that combine genetics with viral and immunologic factors in the pathogenesis of SLE. The experimental model has accelerated the development of new methods for the treatment of this serious disease. Important new information has begun to appear from research into the other "collagen diseases": (1) immune complexes of Australia antigen (from hepatitis virus) and its antibody in some patients with polyarteritis (inflammation of arteries in many organs); (2) the efficacy of cyclophosphamide in the treatment of Wegener's granulomatosis; (3) abnormalities of the microvasculature and autonomic nervous system in systemic sclerosis, or scleroderma; (4) the discovery that lymphokines, derived from the lymphocytes of patients with polymyositis (inflammatory destruction of muscles), can injure muscle cells grown in tissue culture.

A very exciting research finding appeared in 1973 concerning the pathogenesis of the spondylitic group of rheumatic diseases. Investigators in London and Los Angeles reported that 80 to 95 per cent of patients with ankylosing spondylitis (articular inflammation of the vertebral column producing a fixed spine) had a certain histocompatibility antigen (HL–A) W27, as compared to 5 to 6 per cent in control populations. A number of disorders have been associated clinically to varying degrees with ankylosing spondylitis; and in several of them high frequencies of the W27 antigen have been reported this year: 76 to 96 per cent in Reiter's disease (arthritis, urethritis and conjunctivitis); 55 per cent in acute anterior uveitis (eye inflammation); high percentages in small series of ulcerative colitis or psoriasis with spondylitis; and most recently, 42 per cent in juvenile arthritis. Not only does this provide us with an important clue to the pathogenesis of these various disorders, but the opportunity is provided for early detection and to identify susceptible persons even before the disease appears.

The progress of orthopedic surgery in the treatment of arthritis has been astounding. Total replacement of the arthritic hip has been an unqualified success; it has been made possible by research on new plastics for embedding the prosthesis and the optimal design and materials of the prosthesis itself. Thousands of patients with drastic restriction of activity have been restored to comfortable and normal lives. The bioengineers continue to search for the most functional and durable materials; and have made significant progress in the design of total knee replacements; hundreds of artificial knees have been placed in arthritis patients. New designs are being developed for artificial shoulders, elbows and wrists. Silicones implants are being tested widely in the surgical treatment of hands deformed by arthritis. Orthopedic research into the biochemistry and bio-

physics of cartilage and bone shows promise of generating data important for our understanding of selected rheumatic diseases.

My intent in reviewing the research accomplishments and activities in the rheumatic disease field with you today is to share with you the excitement and optimism that my colleagues in rheumtaologic research around the nation and I experience as we view the opportunities for research accomplishments in furthering knowledge in several areas of rheumatic disease. A productive momentum has been created, but it is now seriously endangered. Support for research and research training in arthritis and related diseases has remained static or decreased slightly from FY 1972 to FY 1975 in specific dollar amounts. With the tragic reduction in purchasing power by inflation, there is a drastic reduction in support for research in the rheumatic diseases. Tre President's budget for FY 1975 allots only $13,860,000 for all NIAMDD activities in the arthritis field. This is intolerable.

There is also a critical manpower shortage in rheumatology. The maximal number of rheumatologists in the nation is 2,000. With 20,000,000 persons having arthritis, the rheumatologist to patient ratio is thus estimated at 1:10,000. The needs both for more rhematologists and for greater efficiency in their work, by developing new programs and professionals, are clear.

The manpower shortage is the result of both past indifference and recent cutbacks in training grant support for arthritis. The number of medical schools receiving such support from the NIAMD increased from 4 in 1955 to 43 in 1962; and then was reduced to 40 in 1966, and to only 27 in 1972, and are now being entirely eliminated. One-third of the teaching hospitals in the United States have no Rheumatology Division. New medical schools are finding it difficult to find trained rheumatologists to develop treir programs in artritis. At a time when there has been created an exciting climate of arthritis research with promise of major advances in immunology, virology and experimental models, and with the great need for more practicing trained rheumatologists, the Federal effort is extremely disappointing and discouraging.

Mr. Chairman and Members of the Committee, it is essential to provide within the NIAMDD the necessary support for adequate staff to administer and promote the research and training programs in the field of rheumatic diseases. We urge you to specify the creation of the office of an Associate Director for Arthritis and Related Musculoskeletal Diseases, so that the Institute may formulate plans and programs, utilizing both the grant and contract mechanisms, for mounting the appropriate research and training efforts which are so clearly indicated by the unmet needs in this field.

Dr. Engleman will discuss in depth with you our thoughts about Arthritis Centers. It is our belief that the majority of the problems associated with the field of rheumatic diseases can best be resolved by a team effort of physicians, surgeons, allied health personnel, researchers and academicians working collectively at various regionally located teaching institutions throughout the country. Teams which are inter-related in their research, clinical and training efforts can contribute to a nationwide arthritis data bank in which would be deposited all essential information on those arthritis patients seen by all The Rheumatic Disease Units (or Centers). These teams would have multiple responsibilities and tasks including: both basic and clinical research; training of the physicians who will later be joining these teams as researchers-teachers-clinicians; the education of medical students, interns, residents and the physicians responsible for the primary care of most arthritis patients; and the demonstration of optimal team management of the arthritis patient, especially those who are severely afflicted.

We know today that more and more physicians are becoming aware of their need to know more about arthritis and related diseases from the attendance at continuing education seminars hosted by the chapters of The Arthritis Foundation, at national and regional meetings of the American Rheumatism Association, and from the requests for professional training materials on arthritis such as the recent series of clinical slides on arthritis for use by medical schools, and the new Primer on Arthritis the demand for which is triple that of previous editions. We are still, however, lacking in the most important resource for our medical schools.

A survey of the professional manpower in arthritis conducted for the Arthritis Foundation in 1972, by the management consulting firm of Cresap, McCormick and Paget, Inc., found that only 30 per cent of non-rheumatologist physicians

caring for arthritis patients had ever been exposed to any formal training in the rheumatic diseases. Medical students are, on the average, exposed to the rheumatic diseases for less than 12 classroom hours, and only 9 per cent of medical students in the 1972–73 academic year in which the survey was taken participated in rheumatology electives. The survey reported that only 15 per cent of the 2,200 members of the American Rheumatism Association consider arthritis research as their primary occupation. On the other hand, 21 per cent of all clinically-oriented rheumatologists stated that they were full-time members of a medical school faculty. This contrasts with 2 per cent of all physicians nationally. Given the proper financial stimulation, there could well be a rapid growth in the number of rheumatologists being produced both for research or for augmented contact with medical students and house staff.

In sum, then, we have far too few physicians trained in arthritis; and only enough researchers to staff some 27 medical institutions at a nominal level, and another 20 at extremely unsatisfactory levels. The manpower shortage in The Allied Health field is even more critical. What is needed in order to change dramatically the approach to the investigation of arthritis and to accelerate the speed to which new knowledge about these diseases is intelligently applied is a new program. The programs in arthritis to date by both federal and other agencies have been only fragmentary and entirely inadequate. It is for all these reasons and others to be discussed by my colleagues that the provisions of The Arthritis Prevention, Treatment, and Rehabilitation Act are so essential and so constructive. The Act provides for the first time a systematic attack against the ravages of these crippling and painful illnesses.

PROFESSIONAL MANPOWER IN RHEUMATOLOGY

THE ARTHRITIS FOUNDATION

January 1973

INTRODUCTION

This chapter sets forth the objectives and scope of the study, the approach used in conducting it, and the outline of the report.

OBJECTIVES AND SCOPE

- This study was undertaken pursuant to a resolution of the Executive Committee of the Arthritis Foundation (acting on a recommendation by the Medical Administrative Committee) calling for a survey of existing professional manpower in rheumatology, the need for additional manpower and the order of magnitude of cost of meeting that need.
  - The overall objective was to develop a document which would provide background for discussions with legislators, health officials and others concerned with rheumatic diseases, and which would also serve as a planning base for resource allocation by the Foundation.
- The specific objectives of the study were to:
  - Provide estimates of the current prevalence of arthritis and related diseases in the United States and background data on the economic impact of such diseases
  - Develop a profile of current professional manpower in the United States concerned with arthritis
  - Develop a profile of current training for health professionals concerned with arthritis
  - Provide estimates of the order of magnitude of funds required to close the gap between existing patient care and professional training needs and available manpower resources.
- The scope of the study was specifically limited in two respects.
  - Emphasis in the study was placed on the acquisition, synthesis and evaluation of data collected by others and on the experience and judgment of individuals knowledgeable in rheumatology.

- The study included the identification and analysis of trends indicated by recent data, but did not include historical inquiries.

APPROACH

- Throughout the study, the study team relied heavily on the professional advice and assistance of the health professionals on the Manpower Study Committee, American Rheumatism Association Section, Arthritis Foundation, and the collaboration of the National Institute of Arthritis, Metabolism and Digestive Diseases (NIAMDD).

  - The Manpower Study Committee included:

    K. Frank Austen, M.D. (Chairman) - Bayles Professor of Medicine, Harvard Medical School and Physician-in-Chief, Robert B. Brigham Hospital

    Daniel J. McCarty, M.D., F.A.C.P. - Professor of Medicine, University of Chicago School of Medicine

    William M. Mikkelsen, M.D. - Associate Professor of Internal Medicine, Rackham Arthritis Research Unit, University of Michigan School of Medicine

    Roland W. Moskowitz, M.D. - Associate Professor of Medicine, Case Western Reserve School of Medicine

    Harry Robinson, Sc.D. - Associate Professor and Chief, Section of Biostatistics, University of Tennessee College of Medicine

    Frank R. Schmid, M.D. - Professor of Medicine and Chief, Section on Arthritis and Connective Tissue Diseases, Northwestern University School of Medicine

    Lawrence E. Shulman, M.D., Ph.D. - Associate Professor of Medicine and Director, Connective Tissue Division, The Johns Hopkins University School of Medicine

    Ronnie E. Townsend, M.P.H. - Career Development Officer, Office of Air Programs, Environmental Protection Agency

Homer D. Venters, M.D. - Professor of Pediatrics, University of Minnesota Medical School and Head, Department of Pediatrics, St. Paul - Ramsey Hospital

Max Weiner, Ph.D. - Director, Center for Advanced Study in Education, City University of New York

Donald D. Weir, M.D. - Clinical Associate Professor of Rehabilitation Medicine, State University of Iowa College of Medicine and Medical Director, Rehabilitation Center, St. Lukes Hospital, Cedar Rapids.

Thomas E. Weiss, M.D. - Clinical Professor of Medicine, Tulane University School of Medicine

Nathan J. Zvaifler, M.D. - Professor of Medicine, University of California (San Diego) School of Medicine

William H. Batchelor, M.D. (ex officio) - Training Grants and Fellowship Officer, National Institute of Arthritis, Metabolism and Digestive Diseases

David D. Shobe (ex officio) - Acting Medical Administrator, The Arthritis Foundation

J. Sydney Stillman, M.D. (ex officio) - Immediate Past President, American Rheumatism Association Section, The Arthritis Foundation and Professor of Medicine, Harvard Medical School.

- A review of the literature and discussions with members of the Manpower Study Committee revealed that comparatively few current data directly applicable to the study were available.

  - The most comprehensive recent source of data on the prevalence and economic impact of arthritis in the United States is the 1969 Health Interview Survey undertaken by the Health Interview Survey Section, National Center for Health Statistics, Health Services and Mental Health Administration, Department of Health, Education and Welfare.

    - o These data are based on household interviews of the civilian, noninstitutional population.

    - o As of January 1973, however, only provisional, unpublished data were made available to us for inclusion in the report.

- Since the available data did not provide adequate information for the development of a profile of existing manpower resources in rheumatology, two questionnaires were prepared and mailed to substantial samples of physicians.

  - A questionnaire concerning professional training, patient information, organizational setting for practice, and the utilization of allied health professionals was mailed to a 50 per cent (1,012) random sample of American Rheumatism Association members residing in the United States.

    - o Examination of the listings of rheumatologists in the 1971 "Directory of the American College of Physicians" and the 1971 "Directory of the American Society of Internal Medicine" revealed that the American Rheumatism Association listing was by far the largest and most comprehensive.

    - o As shown in Exhibit I-1 on the following page, 60 per cent of the questionnaires were returned - an unusually high return rate for a survey such as this.

  - A second questionnaire concerning the professional training and rheumatology practices of 1,056 physicians in selected specialties presumed to treat rheumatology patients was also mailed.

    - o American Medical Association listings by specialty provided the source of this sample of orthopedic surgeons, physiatrists, internists, family practitioners, general practitioners and pediatricians.

    - o The response rate to this questionnaire was 21 per cent - somewhat more than had been anticipated.

- Since the available data were not adequate for the development of a profile for professional training in rheumatology, three questionnaires concerning the content, scope, duration and productivity of existing training programs for physicians and allied health professionals were prepared and mailed.

MAILINGS AND RESPONSE RATE TO QUESTIONNAIRES ON PROFESSIONAL MANPOWER IN RHEUMATOLOGY

Group Surveyed	Number	Mailing Date	Number Of Responses(a)	Response Rate
Physicians In Rheumatology	1,012	March 10	603	60%
Physicians In Orthopedic Surgery, Physical Medicine, Internal Medicine, Family Practice, General Practice And Pediatrics	1,056	April 5	220	21
Arthritis Clinical Centers And Programs	108	March 8	108	100
Veterans Administration Hospitals	78	March 8	39	50
Schools Of Nursing				
With associate degree programs	91	March 9	59	65
With baccalaureate programs	40	March 9	27	68
With diploma programs	95	March 9	57	60
Schools Of Physical Therapy	52	March 8	42	81
Schools Of Occupational Therapy	22	March 8	16	73
Schools Of Social Work	26	March 8	11	42

(a)As of May 16, 1972.

EXHIBIT I-1

INTRODUCTION (Cont'd)

- Questionnaires were sent to each of the 108 accredited medical schools in the United States.
    - o The questionnaires concerned rheumatology training for physicians at all educational levels in the medical schools and their teaching affiliates.
    - o Completed questionnaires were received from 87 per cent (94) of the schools, and less detailed responses to follow-up letters were received from all of the remaining schools.
- Similar questionnaires were mailed to a 50 per cent (78) random sample of all Veterans Administration Hospitals.
    - o The response rate to this questionnaire was 50 per cent.
- Questionnaires concerning the training offered in rheumatology for students of the allied health professions were mailed to 326 educational institutions.
    - o Questionnaires were mailed to a 20 per cent random sample (226) of nursing institutions offering baccalaureate, associate degree, and diploma programs, 63 per cent of which were completed and returned.
    - o Questionnaires were mailed to the 52 colleges and universities offering certificate, bachelor's or master's degree programs in physical therapy, 81 per cent of which were completed and returned.
    - o Questionnaires were mailed to a 50 per cent random sample (22) of the colleges and universities offering courses in occupational therapy, 73 per cent of which were completed and returned.
    - o Questionnaires were mailed to a 33 per cent random sample (26) of the graduate schools of social work, 42 per cent of which were returned.

- In addition, the Ochsner, Cleveland, Lovelace and McBride (Oklahoma) Clinics and the Kaiser Permanente Medical Group were contacted, but only the Lovelace and McBride Clinics responded to the full questionnaire.

- Letters of inquiry were sent to all five schools of osteopathy accredited by the American Osteopathic Association; three schools responded.

- Five colleges of podiatric medicine were contacted, and all responded.

- In addition, letters inquiring on the type and scope of continuing education activities were sent to 20 local societies affiliated with the American Rheumatism Association and to all chapters of the Arthritis Foundation.

    - o Only eight of the societies and three of the local chapters have responded.

- The data provided by the Health Interview Survey, the letters and questionnaires described above, recent literature, and the files of the Arthritis Foundation and the NIAMDD are compiled, analyzed and interpreted in this report.

ORGANIZATION OF THIS REPORT

- The remainder of this report is divided into four chapters, as follows:

    II - Prevalence And Economic Impact Of Arthritis And Related Diseases, which presents and interprets the data from the 1969 Health Interview Survey

    III - Profile Of Professional Manpower In Rheumatology, which presents the results of the questionnaires distributed as part of this study

    IV - Profile Of Professional Training In Rheumatology, which presents results on the type, duration, special funding arrangements and projected output of training programs

    V - Conclusions, which presents conclusions drawn on the basis of material presented in the other chapters.

PREVALENCE AND ECONOMIC IMPACT OF ARTHRITIS AND RELATED DISEASES

This chapter presents and interprets the latest available data from the 1969 Health Interview Survey concerning the prevalence and economic impact of arthritis and related diseases. These data have yet to be published by the National Center for Health Statistics of the Health Services and Mental Health Administration and should be considered as provisional. The data are based on verbal statements made to interviewers, and only specific mention of a disease or its symptoms were counted.

PREVALENCE OF ARTHRITIS AND RELATED DISEASES

- The Survey indicated that at least 20,230,000 people in the United States were suffering from arthritis, rheumatism, gout and other arthritis-like conditions.
  - The largest category, arthritis, accounted for 18,315,000 of the cases.
    - o The Survey used the International Classification of Diseases definitions and included in this category acute arthritis (pyogenic and nonpyogenic), adult and juvenile rheumatoid arthritis, spondylitis, osteoarthritis and allied conditions, as well as traumatic arthritis and unspecified arthritis.
  - Rheumatism accounted for 992,000 cases.
    - o This category included polymyositis, dermatomyositis, fibrositis and other unspecified rheumatisms, excluding lumbago and torticollis.
  - Gout accounted for 968,000 cases.
    - o This category includes 215,000 persons also counted under other categories.
  - "Arthritis-like conditions" accounted for 170,000 cases (mostly psoriatic arthritis).

- Not included in the total prevalence data are patients suffering from systemic lupus erythematosus, progressive systemic sclerosis, polyarteritis, and periarteritis.

    - o Discussions with members of the Manpower Study Committee and other knowledgeable individuals suggest that the number of persons with this last group of serious, and often life-threatening, diseases may well be between 100,000 and 400,000.

- Double-counting has been eliminated from the statistics other than those for gout; that is, a patient with two distinct kinds of rheumatic disease would be counted only once.

- In general, rheumatic diseases are much more common among the elderly than among the young, and they tend to afflict more females than males, as shown in Exhibit II-1 on the following page.

    - The prevalence of rheumatic diseases as a whole is 22.5 per hundred for people between 45 and 64 years of age and 41.0 per hundred for those over 65.

    - Women are markedly more susceptible to arthritis than are men.

        - o In the over-65 age group, 44.9 per cent of the female population suffers from some form of arthritis, while only 28.7 per cent of the male population in this age group is subject to these diseases.

    - However, the prevalence of rheumatism among females is essentially equivalent to that among males.

    - Gout is more than twice as prevalent among men than it is among women.

- The prevalence of rheumatic diseases also varies by race, as shown in Exhibit II-2.

    - It appears that rheumatic disease is less prevalent among white males than others 65 years of age or older.

PREVALENCE OF ARTHRITIS, RHEUMATISM AND GOUT IN THE UNITED STATES, BY SEX AND AGE GROUP

1969

Sex And Age Group	Arthritis		Rheumatism(a)		Gout		Total Population
	Number (000)	Number Per 100 Persons	Number (000)	Number Per 100 Persons	Number (000)	Number Per 100 Persons	(000)
Both Sexes							
All ages	18,315	9.3	992	0.5	968	0.5	197,422
Under 45	2,923	2.1	237	0.2	230	0.2	138,022
45 to 64	8,308	20.4	406	1.0	498	1.2	40,742
65 and over	7,084	38.0	350	1.9	240	1.3	18,658
Male							
All ages	6,123	6.4	433	0.5	669	0.7	95,002
Under 45	968	1.4	74	0.1	173	0.3	67,609
45 to 64	2,865	14.8	183	0.9	337	1.7	19,402
65 and over	2,291	28.7	177	2.2	159	2.0	7,990
Female							
All ages	12,192	11.9	559	0.5	299	0.3	102,420
Under 45	1,955	2.8	163	0.2	57	0.1	70,413
45 to 64	5,443	25.5	223	1.0	160	0.7	21,339
65 and over	4,794	44.9	173	1.6	81	0.8	10,667

(a)Excludes lumbago and torticollis.

Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

PREVALENCE OF RHEUMATIC DISEASE IN THE
UNITED STATES BY RACE, SEX AND AGE GROUP(a)
(1969)

Age	White			Other(b)		
	Male	Female	Both	Male	Female	Both
	A - Number Of Persons (000)					
All Ages	5,929	11,571	17,500	699	1,279	1,977
Under 45	939	1,858	2,797	112	280	392
45 To 64	2,752	5,151	7,902	329	570	899
65 And Over	2,239	4,562	6,800	258	429	686
	B - Number Per 100 Total Population					
All Ages	7.1	12.9	10.1	6.1	10.0	8.2
Under 45	1.6	3.1	2.3	1.2	2.8	2.1
45 To 64	15.6	26.8	21.4	18.3	27.3	23.1
65 And Over	30.6	46.4	39.6	38.5	51.6	45.7

(a)Excluding those with gout, but including 170,000 with arthritis-like conditions.
(b)Blacks, Orientals and American Indians.
Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

- In tabulating results of the Survey, Hispanic-surnamed individuals were classified as white; blacks, American Indians, and Orientals were classified as "other."

- Prevalence rates by race for specific categories of disease are not yet available.

- There is no marked variation in the prevalence of the three principal disease categories on the basis of geographic region or place of residence, as shown in Exhibit II-3.

  - However, arthritis appears to be more prevalent outside metropolitan areas.

- The prevalence of arthritis and rheumatism is higher among individuals with family income of less than $4,000 than it is among other income groups, as shown in Exhibit II-4.

  - The prevalence of gout, however, is slightly higher in the most affluent group.

  - Presumably, the lower income groups contained a substantial proportion of retired persons, some of whom are not, in fact, "poor."

- Rheumatic diseases are most prevalent among retired persons, as shown in Exhibit II-5.

  - The high prevalence of arthritis among women, referred to above, is affirmed by the high prevalence of these diseases among people whose usual activity is keeping house.

  - Unfortunately, the provisional data do not identify the prevalence of these diseases for children under six years of age or for young or middle-aged adults who are so disabled that their usual activity is neither working nor keeping house.

PREVALENCE OF ARTHRITIS, RHEUMATISM
AND GOUT IN THE UNITED STATES, BY GEOGRAPHIC REGION
AND TYPE OF RESIDENCE
1969

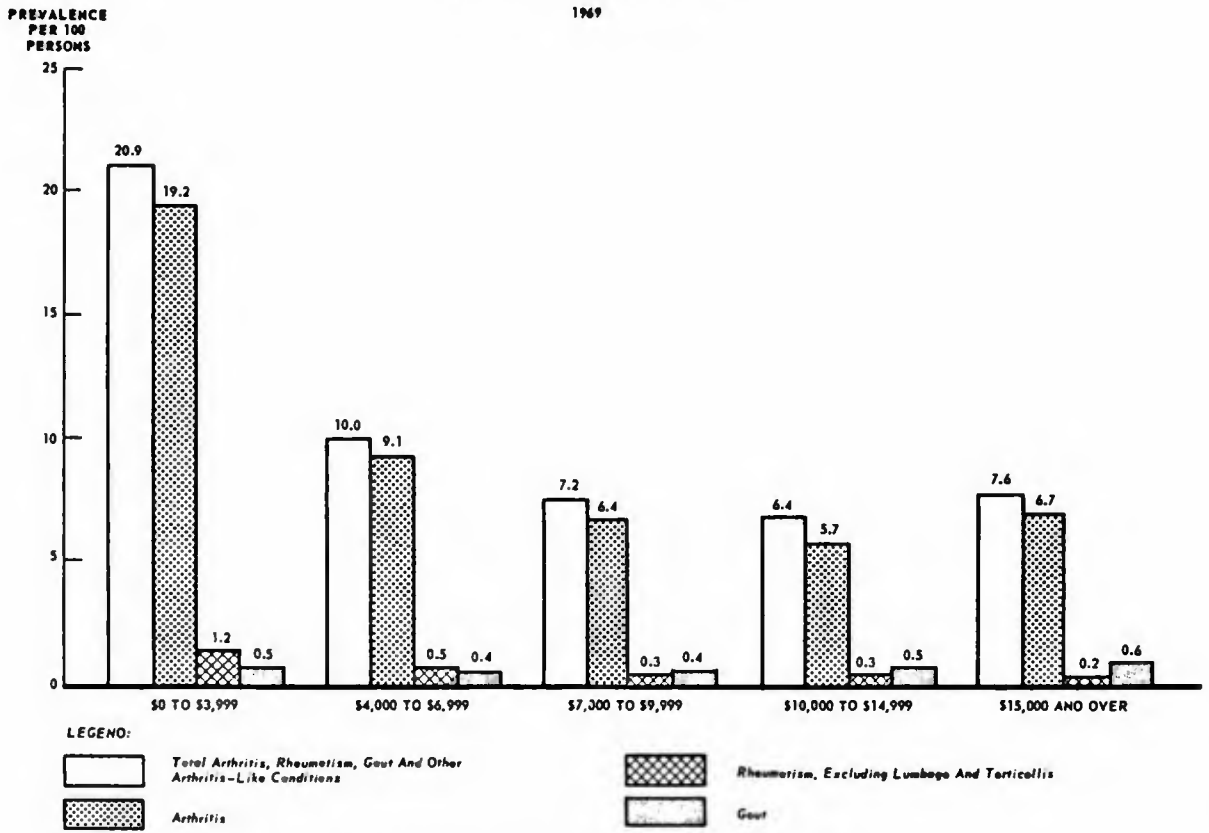
Region Or Type Of Residence	Arthritis		Rheumatism		Gout		Total Population
	Number (000)	Number Per 100 Persons	Number (000)	Number Per 100 Persons	Number (000)	Number Per 100 Persons	(000)
A - By Region							
Northeast	4,322	8.8	223	0.5	265	0.5	49,071
North Central	5,109	9.2	252	0.5	243	0.4	55,455
South	6,127	10.2	365	0.6	266	0.4	60,315
West	2,775	8.4	153	0.5	194	0.6	32,582
B- By Type Of Residence							
Standard Metropolitan Statistical Areas(a)	11,130	8.5	530	0.4	685	0.5	129,590
Other, Nonfarm	6,120	10.4	386	0.7	254	0.4	59,109
Other, Farm	1,065	12.2	77	0.9	n.a.	n.a.	8,723

n.a. - not available.
(a)Standard metropolitan statistical areas contain at least one central city of 50,000 population or greater, or two adjoining cities which form a single community with a population of at least 50,000.
Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

EXHIBIT II-3

PREVALENCE OF ARTHRITIS, RHEUMATISM AND GOUT IN THE UNITED STATES, BY FAMILY INCOME GROUPS

1969

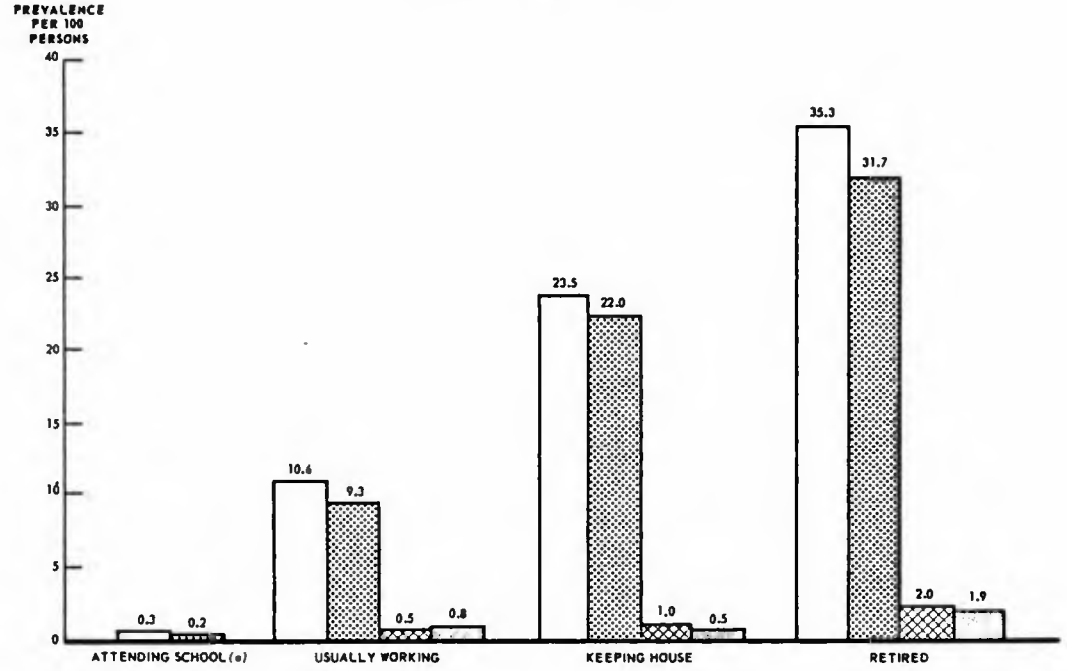


Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

EXHIBIT II-4

PREVALENCE OF ARTHRITIS, RHEUMATISM AND GOUT IN THE UNITED STATES, BY USUAL ACTIVITY GROUPS

1969



(a) Figures on rheumatoid arthritis, rheumatism and gout not available.

Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

ECONOMIC IMPACT OF ARTHRITIS AND RELATED DISEASES

- The Health Interview Survey provides some indication of the economic impact of arthritis and related diseases.
  - Exhibit II-6 indicates the days of restricted activity, bed-days and lost workdays due to rheumatic disease.
  - However, days of restricted activity and work loss appears to be significantly understated because of the definitions used; therefore, they do not provide an adequate basis for estimating the loss of economic productivity for which rheumatic diseases are responsible.
    - o Restricted activity days were defined as days in which an individual has reduced his usual activity.
    - o Lost workdays include only nonworking days of individuals who were then in the labor force and employed from time to time; they do not include the nonworking days of housewives, students and the disabled.
  - Also, the data do not include patients suffering from systemic lupus erythematosus, progressive systemic sclerosis, polyarteritis, and periarteritis - rheumatic diseases which can be quite disabling.

RESTRICTED ACTIVITY DAYS, LOST WORKDAYS AND BED-DAYS OF PERSONS WITH RHEUMATIC DISEASES, BY SEX AND AGE GROUP
1969

Sex And Age Group	Restricted Activity Days Due To: Rheumatic Disease Number (000)	Rheumatic Disease Days Per Person	All Causes, Days Per Person(b)	Lost Workdays Due To:(c) Rheumatic Disease Number (000)	Rheumatic Disease Days Per Person	All Causes, Days Per Person(b)	Bed-Days Due To: Rheumatic Disease Number (000)	Rheumatic Disease Days Per Person	All Causes, Days Per Person(b)
A - Rheumatic Diseases Other Than Gout									
Male									
Under 45	10,096	9.6	25.2	1,951(c)	2.2(c)	10.5(c)	2,298	2.2	9.2
45 to 64	33,935	11.0	36.4	5,974	2.5	12.5	10,556	3.4	13.1
65 and over	30,254	12.1	42.4	n.r.	n.r.	9.0	10,238	4.1	16.2
All ages	74,286	11.2	36.9	9,416	2.4	11.5	23,091	3.5	13.6
Female									
Under 45	15,306	7.2	30.0	n.r.	o.r.	7.7(c)	2,862	1.3	11.2
45 to 64	61,928	10.8	34.3	3,671	1.5	9.9	17,548	3.1	12.1
65 and over	86,328	17.3	48.4	n.r.	o.r.	4.3	27,162	5.4	18.2
All ages	163,562	12.7	39.1	4,732	1.3	8.7	47,573	3.7	14.3
Both Sexes									
Under 45	25,403	8.0	28.4	2,786(c)	1.6(c)	9.1(c)	5,160	1.6	10.6
45 to 64	95,863	10.9	35.1	9,591	2.0	11.2	28,104	3.2	12.5
65 and over	116,582	15.6	46.4	1,771	1.7	7.1	37,400	5.0	17.5
All ages	237,848	12.2	38.3	14,147	1.9	10.1	70,664	3.6	14.1
B - Gout									
Both Sexes, All Ages	7,781	10.3	n.e.	n.a.	n.a.	o.a.	4,593	4.8	n.a.

o.r. - too small a number to be statistically reliable.
n.e. - not available.
(c)For persons currently employed only.
(b)Including rheumatic diseases.
(c)For persons aged 17 to 44 only.
Source: Provisional, unpublished data from the 1969 Health Interview Survey, National Center for Health Statistics, HEW.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY

This profile of professional manpower in rheumatology includes physicians with specialization or significant interest in rheumatology, physicians in other specialties who can reasonably be expected to treat patients with arthritis and related diseases, and allied health professionals in rheumatology.

This profile is based primarily on data which have been derived from mail questionnaire surveys conducted by Cresap, McCormick and Paget Inc. Provisional, unpublished data from the 1969 Health Interview Survey are also included. Whenever data other than those derived from CMP surveys are cited, the source is stated in the text.

Characteristics of the profile of physicians include basic specialization, professional training in rheumatology, size and constitution of rheumatology practice, and referral patterns. For physicians specializing or having a significant interest in rheumatology, the profile also includes selected demographic data, professional orientation, organizational setting for practice, and teaching activities. For allied health professionals in rheumatology, the profile is limited to the current utilization of various types of allied health professionals (in settings where their principal concern may reasonably be expected to be the care of patients with arthritis and related diseases) and to the unrealized opportunities for utilization of allied health professionals, as indicated by practicing physicians.

To avoid underestimating the number of physicians specializing in arthritis and related diseases, the 2,024 physicians practicing in the United States who have shown sufficient interest in rheumatology to join the American Rheumatism Association are treated as "rheumatologists." Presumably, some members of the Association have only a minor interest in rheumatology and do not, in fact, specialize in the field. Conversely, some specialists in rheumatology may not have chosen to join the Association. However, comparison with data derived from the survey of physicians in various medical specialties (as identified by American Medical Association listings) suggests that the estimate of 2,024 rheumatologists is high and thus, for the purposes of this report, conservative.

RHEUMATOLOGISTS

Formal Training

- The basic specialty training for most rheumatologists has been in internal medicine.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

- Internists comprised 79. 7 per cent of the respondents.
    - o Of these, 58. 3 per cent claimed board certification, 31. 1 per cent claimed board eligibility, and 10. 6 per cent claimed board qualification.
- Orthopedic surgeons comprised 11. 8 per cent of the respondents.
    - o Of these, 78. 5 per cent claimed board certification, 3. 9 per cent claimed board eligibility, and 17. 6 per cent claimed board qualification.
- Physiatrists comprised 5. 0 per cent of the respondents.
    - o Of these, 90 per cent claimed board certification, 3. 4 per cent claimed board eligibility, and 6. 7 per cent claimed board qualification.
- Pediatricians comprised 1. 7 per cent of the respondents.
    - o Of these, 60 per cent claimed board certification, 20 per cent claimed board eligibility, and 20 per cent claimed board qualification.
- The remaining 1. 8 per cent indicated other specialties.
    - o All of these indicated that they were at least board-qualified.

- Formal training in rheumatology has most often been obtained through fellowships rather than residencies; however, 35. 6 per cent of the respondents did not indicate what sort of formal training, if any, they had received in rheumatology.
    - Almost 80 per cent of those who indicated some formal training in rheumatology had received fellowship training, and the average duration of this training was 23. 7 months.

- Thirty-nine per cent received residency training, and the average duration was 15.2 months.

- Almost a quarter of the respondents to the training question indicated that they had participated in some form of continuing education in rheumatology.

Age And Geographic Distribution

- The age distribution of rheumatologists appears to compare favorably with that of physicians in general.

  - The age distribution of the rheumatologists responding to this question is compared below with the age distribution of physicians listed in the American Medical Association Directory for 1970:

Age Group	Per Cent Of Rheumatologists	Per Cent Of Physicians In General
Under 30	0.4%	11.5%
30 To 39	28.5	27.0
40 To 49	35.9	24.6
50 To 59	20.2	17.5
60 To 69	10.7	12.0
70 And Over	4.5	7.4

  - The relatively low percentage of rheumatologists under 30 may be explained by the fact that some would not have begun and many would not have finished their rheumatology training before the age of 30.

  - The large percentage of rheumatologists in the 40 to 49 age group suggests that rheumatology is an increasingly attractive field to physicians.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

- There appears to be a serious geographic maldistribution of rheumatologists in the United States.
  - As shown in Exhibit III-1, Idaho, Nevada and South Dakota have no rheumatologists, and there are five or fewer rheumatologists in Alaska, Delaware, Maine, Mississippi, Montana, New Hampshire, New Mexico, North Dakota, Rhode Island, South Carolina, Utah, West Virginia and Wyoming.

Size And Constitution Of Rheumatology Practice

- Results of the survey suggest that 85 per cent of the rheumatologists are engaged in clinical practice, while approximately 15 per cent (300 physicians) work primarily in research.
- Only 3.1 per cent of the people who know that they have arthritis or a related disease appear to be under the care of rheumatologists.
  - The results of the survey suggest that rheumatologists in clinical practice collectively care for approximately 633,000 rheumatology patients (389 patients per rheumatologist), or only 3.1 per cent of the total number of potential patients identified in the 1969 Health Interview Survey.
  - However, provisional, unpublished data from the Health Interview Survey indicate that, of the 19,477,000 persons suffering from various forms of rheumatic disease (excluding gout and the collagen diseases), only 85,000 (0.4 per cent) are under the care of a rheumatologist for their rheumatic disease.
    - o This figure may be understated because many people interviewed may not have been aware that the physicians treating them were rheumatologists, as the specialty is not yet clearly defined.
- It appears that much of the practice of the clinically oriented rheumatologists centers around the care of patients with acute, crippling or fatal disease entities.
  - The 12 disease entities most often treated by these physicians in descending order of frequency are:
    - o Adult rheumatoid arthritis

DISTRIBUTION OF AMERICAN RHEUMATISM ASSOCIATION MEMBERS

1972

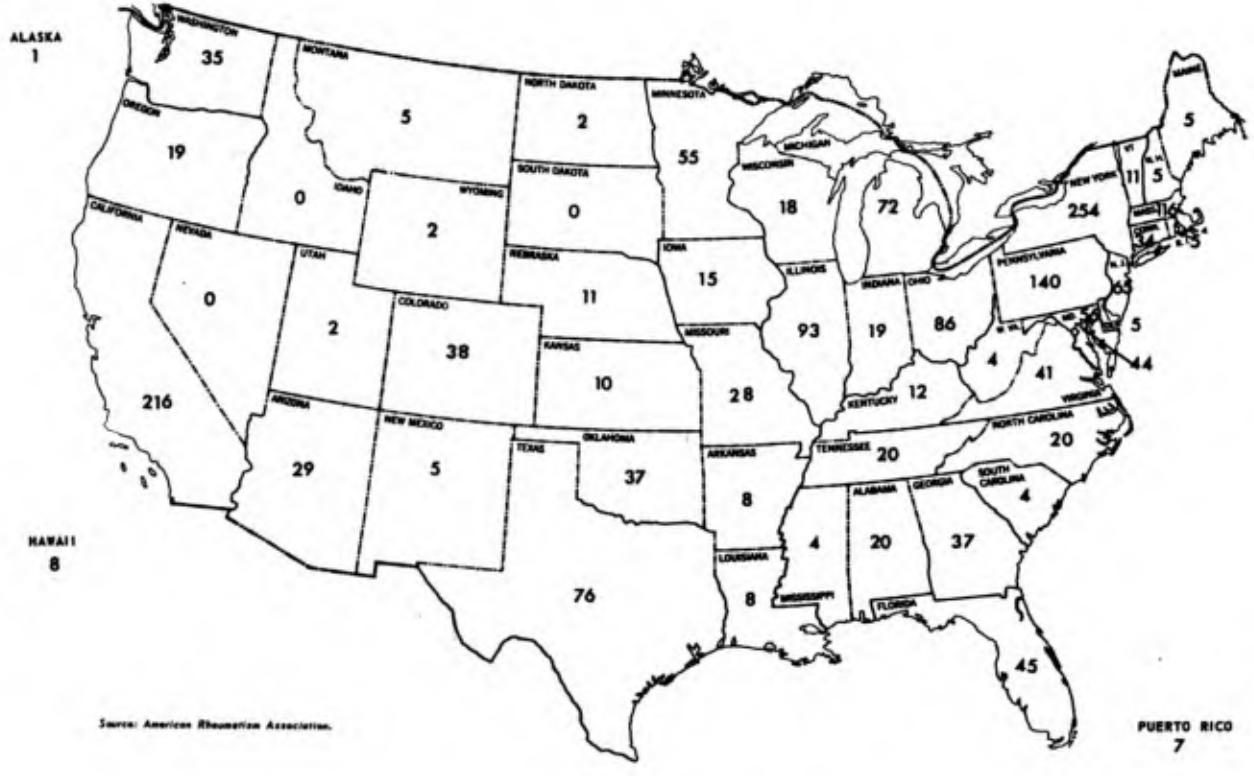


EXHIBIT III-1

- o Systemic lupus erythematosus
- o Osteoarthritis and degenerative joint disease
- o Gout
- o Scleroderma (progressive systemic sclerosis)
- o Polymyositis and dermatomyositis
- o Bursitis, tendinitis and peritendinitis
- o Ankylosing spondylitis
- o Fibrositis
- o Psoriatic arthritis
- o Reiter's syndrome
- o Juvenile rheumatoid arthritis.

- The special skills of some rheumatologists do not appear to be utilized effectively.

  - The table below indicates that one-half of the responding members of the American Rheumatism Association devote 50 per cent or less of their practice time to rheumatology.

Per Cent Of Practice Time Devoted To Rheumatology	Per Cent Of Responding Rheumatologists
0 To 25%	27%
26 To 50	23
51 To 75	13
76 To 100	37

- This apparent low rate of utilization of rheumatologists in rheumatology can be partially explained by the fact that some of the rheumatologists, particularly those that are not internists, may have a variety of practice interests.

    - o In the opinion of the Manpower Study Committee, it would not be typical for an orthopedic surgeon or pediatrician with an intense interest in rheumatology to devote his entire practice to rheumatology.

- It also appears that patterns of referral to rheumatologists are not always well developed.

    - o Fifty-four per cent of the responding members of the American Rheumatism Association indicated that fewer than half of their new patients were referred to them by other physicians.

    - o Only 15 per cent claim to maintain an exclusive referral practice.

- A study by the Massachusetts Chapter of the Arthritis Foundation, conducted in 1968 and 1969, found that some physicians with little or no training in rheumatology were reluctant to refer their rheumatic disease patients to well-qualified and readily available rheumatologists for diagnostic consultations, even when there would be no charge to the patient, because they feared economic loss or possible embarrassment.

- The survey of nonrheumatologists in selected specialties conducted as a part of this study (discussed subsequently in this chapter) also suggests that many physicians are reluctant to refer their patients to rheumatologists.

Organizational Setting For Practice

- Rheumatologists are more likely to be full-time members of a medical school faculty and are more likely to participate in a group practice (as opposed to solo private practice) than physicians in general.

    - The table below shows the percentage of responding clinically oriented rheumatologists working in five different organizational settings compared with 1969-70 data for physicians in general.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

Organizational Setting	Per Cent Of Clinically Oriented Rheumatologists	Per Cent Of All Physicians(a)
Solo Private Practice	34%	69%
Specialty Group Or Partnership	21	7
Multi-Specialty Group Or Partnership	14	11
Full-Time Hospital Staff	10	11
Full-Time Medical School Faculty	21	2

(a)As determined by the Center for Health Services Research and Development, American Medical Association.

- The particularly high percentage of rheumatologists on medical school faculties suggests a relatively rapid growth potential in rheumatology.

- Approximately 63 per cent of the rheumatologists appear to have some level of teaching responsibility.

    - Of these, almost all teach medical students, interns and residents, but only about half teach fellows, practicing physicians and allied health professionals.

- Sixty-one per cent of all rheumatologists regularly participate in rheumatology teaching rounds in hospitals; they average seven rounds per month.

- Seventy per cent regularly operate or participate in organized rheumatology clinics; they average 6. 5 sessions per month.

- Regardless of organizational setting, the rheumatologists appear to have ready access to necessary diagnostic facilities.

    - Almost all the respondents indicated that they have access to reliable diagnostic laboratory services in rheumatology for such tests as rheumatoid factor, antinuclear antibodies, hemolytic complement and joint fluid analysis.

- Adequate treatment facilities are somewhat less frequently available for rheumatology patients.

  - The percentage of respondents reporting the ready availability of treatment services in their areas of practice were as follows:

Treatment Service	Per Cent Reporting Availability
Physical Therapy	97.6%
Mobile Physical Therapy Units	16.2
Occupational Therapy	81.9
Reconstructive Joint Surgery	92.8
Organized Rheumatology Clinics	81.3
Rehabilitation Centers	74.7
Separate Rheumatology Inpatient Units	56.4

NONRHEUMATOLOGISTS

- A representative sample of physicians in key specialties who might be expected to encounter significant numbers of rheumatic disease patients was surveyed by CMP to permit comparison of their training in rheumatology and their rheumatic disease practice with the training and practice of rheumatologists.

Formal Training In Rheumatology

- Only 31 per cent of the nonrheumatologists responding indicated that they had any formal exposure to rheumatology in the course of residency or fellowship training.

  - Responses concerning the duration of formal training in rheumatology are lacking in face validity.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

- Only 13 per cent of the physicians reported participation in some form of continuing education in rheumatology.

Size And Constitution Of Rheumatology Practice

- Approximately three-fourths of the responding nonrheumatologists indicated that they had rheumatic disease patients under their care.
  - The average number of rheumatic patients was 73.3.
- Provisional, unpublished data from the 1969 Health Interview Survey indicate that, although 79.5 per cent of the persons with some form of rheumatic disease (excluding the collagen diseases) made one or more physician visits per year, only 20.3 per cent (4,160,000) were under the care of a nonrheumatologist for their rheumatic disease, per se.
  - In addition, 75 per cent of the persons with rheumatic disease (excluding the collagen diseases) had their conditions first diagnosed by a physician; at least 21 per cent performed a self-diagnosis or had their condition diagnosed by a friend or relative.
- As was suggested earlier in this chapter, a significant portion of the physicians responding indicated that they do not refer rheumatic disease patients to rheumatologists for diagnosis or treatment.
  - Forty-two per cent of the physicians indicated that they do not refer juvenile rheumatoid arthritis or collagen disease patients to rheumatologists.
  - Eighty-nine per cent indicated that they do not refer gout or osteoarthritis patients to rheumatologists.
  - However, it is assumed that these physicians would arrange consultations if specifically requested to do so by a patient.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

ALLIED HEALTH PROFESSIONALS

- Provisional, unpublished data from the 1969 Health Interview Survey indicate that 7.3 per cent of those persons suffering from rheumatic disease have been treated by a physical therapist, and 1.2 per cent have been treated by an occupational therapist, but 95.5 per cent have never been seen by a social worker.

- Further information on the current utilization and unrealized opportunities for allied health professionals was derived from the surveys of medical schools, Veterans Administration hospitals, and rheumatologists, as discussed below.

Clinical Centers

- Sixty-five medical schools with arthritis clinical centers or other organized rheumatology units indicated the utilization of a total of 133 full-time-equivalent physical therapists, 52 occupational therapists, 60 social workers and 222 registered nurses in caring for rheumatology patients, per se.

  - Thus, the average rheumatology unit affiliated with a medical school employs approximately two physical therapists, one occupational therapist, one social worker and two registered nurses.

Veterans Administration Hospitals

- Thirty-nine Veterans Administration hospitals reported employing a total of fifteen physical therapists, seven occupational therapists, four social workers and one registered nurse specifically for rheumatology patients.

Private Practice

- Approximately 48 per cent of the rheumatologists in private practice (with a group or solo) reported the employment of allied health professionals in their offices.

  - Twenty-six per cent of the rheumatologists in private practice employed physical therapists, 7 per cent employed occupational therapists, 9 per cent employed social workers and 37 per cent employed registered nurses.

PROFILE OF PROFESSIONAL MANPOWER IN RHEUMATOLOGY (Cont'd)

Unrealized Opportunities For Allied Health Professionals

- The rheumatologists surveyed suggested that there were significant opportunities for greater utilization of well-trained allied health professionals, particularly in:
  - Home physical therapy
  - Patient training with self-help devices
  - Routine follow-up evaluations.
- The rheumatologists also reported shortages of physical therapists, occupational therapists and social workers (in that order), but not of registered nurses.

PROFILE OF PROFESSIONAL TRAINING IN RHEUMATOLOGY

This profile of the rheumatology training available to health professionals of various educational levels emphasizes the type and duration of programs and special funding arrangements. The current and projected output of rheumatology training programs are also discussed in this chapter. Most of the data presented in this chapter have been derived from surveys of medical schools, their affiliated hospitals, Veterans Administration hospitals, and schools of the allied health professions.

TYPE AND DURATION OF TRAINING

- This discussion has been divided into training for medical students, training for residents not specializing in rheumatology, rheumatology traineeships, continuing education programs, and training for allied health professionals.

Rheumatology Training For Medical Students

- On the average, medical students appear to receive 11.6 classroom-hours of preclinical training specifically directed to rheumatology.
  - This average is based on the responses of 58 per cent of the medical schools responding to the survey.
    - o Presumably, the curricular organization in some medical schools would make it exceedingly difficult, if not impossible, to estimate the number of classroom-hours specifically devoted to rheumatology.
- Medical students appear to receive about 10 hours of mandatory clinical training in rheumatology.
  - Only 39 per cent of the medical schools responding to the questionnaire answered this question.

PROFILE OF PROFESSIONAL TRAINING IN RHEUMATOLOGY (Cont'd)

- Electives in rheumatology for medical students were offered by 72 per cent of the medical schools responding to the survey.
  - The reporting schools indicated that a total of 903 students participated in rheumatology electives annually, for an average of 13.7 students per school.
  - Based on these responses, it can be estimated that approximately 950 medical students in all schools took electives in rheumatology in the last year.
    - o This number is equivalent to less than 9 per cent of the medical students enrolled that year.

Rheumatology Training For Residents Not Specializing In Rheumatology

- Several responding medical-school-affiliated residency programs provide mandatory rotation through rheumatology for residents in various specialities other than rheumatology.
  - The number of specialty programs with mandatory rotation and the average duration of rotation are as follows:

Specialty	Number Of Programs	Average Duration Of Mandatory Rotation (Months)
Internal Medicine	15	1.8
Orthopedic Surgery	4	2.5
Physical Medicine	4	2.3
Pediatrics	3	1.0

- Elective rotation through rheumatology for nonrheumatologists is also offered by a number of programs, including some of those which provided mandatory rotation.
  - The number of programs and the average duration of rotation are as follows:

PROFILE OF PROFESSIONAL TRAINING IN RHEUMATOLOGY (Cont'd)

Specialty	Number Of Programs	Average Duration Of Elective Rotation (Months)
Internal Medicine	57	2.3
Orthopedic Surgery	19	2.4
Pediatrics	11	1.8
Physical Medicine	5	2.4

- The reporting schools indicated that 684 residents completed elective rotation through rheumatology in 1971.
    - o Eighty-three per cent of these residents were graduates of American medical schools.

Rheumatology Traineeships

- Responses from all 108 operating accredited medical schools indicate that affiliated programs provided 45 resident positions in rheumatology in 1971.
    - Of these, 42 (93.3 per cent) were filled.
        - o For some of the vacant positions, funds were not available for faculty support, or institutions were not able to recruit sufficient staff.
    - About half were approximately one year in duration; the remainder were for six-month periods.
- The schools reported that their affiliated programs offered 170 fellowships in rheumatology.
    - Of these, 152 (89.4 per cent) were filled in 1971.
    - Of the 152, however, at least 53 were Ph.D.'s, not physicians.
    - The average duration of the fellowships was 18 months.
    - The fellowships offered were equally divided between clinical and research orientations.
- Exhibit IV-1 indicates the number of offered and filled residencies and fellowships in rheumatology in 1971 by medical school affiliation, and lists the source and amount of support for these traineeships.

EXHIBIT IV-1
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RHEUMATOLOGY TRAINEESHIPS AT MEDICAL SCHOOLS
1971

MEDICAL SCHOOL	RESIDENCIES		FELLOWSHIPS		SOURCE OF SUPPORT				
					ARTHRITIS FOUNDATION				
	OFFERED	FILLED	OFFERED	FILLED	(NATIONAL)	(LOCAL)	NIH	RESIDENCY PROGRAM	OTHER
University of Alabama	–	–	3	3	–	$ 10,000	$ 50,000	–	–
University of Arizona	–	–	–	–	–	–	–	–	–
University of Arkansas	–	–	–	–	–	–	–	–	–
Baylor College of Medicine	3	3	1	1	–	–	10,000	$ 20,000	–
Boston University	–	–	5	5	$ 10,000(a)	10,000(a)	20,000(a)	–	–
Brown University	–	–	–	–	–	–	–	–	–
University of California at Davis	–	–	–	–	–	–	–	–	–
University of California at Irvine	–	–	–	–	–	–	–	–	–
University of California at Los Angeles	5	3	10	10	–	36,000	72,000	36,000	$ 57,000
University of California at San Diego	–	–	5	2	8,500	13,000	13,000	–	–
University of California at San Francisco	1	1	5	5	–	–	24,000	–	–
Case Western Reserve University	1	1	1	1	–	–	9,000	–	–
University of Chicago	–	–	5	5	10,000(a)	–	20,000(a)	–	–
Chicago Medical School	–	–	–	–	–	–	–	–	–
University of Cincinnati	1	1	5	5	–	8,000	37,000	7,500	–
City University of New York (Mt. Sinai)	–	–	5	5	–	32,000	–	–	–
University of Colorado	–	–	5	5	–	–	–	20,000	31,000
Columbia University	–	–	5	1	–	10,000(a)	–	–	–
University of Connecticut	1	1	–	–	–	–	–	15,000	–
Cornell University	–	–	5	5	–	11,000	57,000	13,000	12,000
Creighton University	–	–	–	–	–	–	–	–	–
Dartmouth College	–	–	–	–	–	–	–	–	–
Duke University	–	–	5	5	–	–	32,737	–	–
Emory University	–	–	2	5	10,000	–	–	–	7,500
University of Florida (Gainesville)	–	–	–	–	–	–	–	–	–
Georgetown University	–	–	5	5	–	4,000	–	–	29,000
George Washington University (Washington, D.C.)	–	–	–	–	–	–	–	–	–
Medical College of Georgia	–	–	1	1	–	–	–	8,000	–
Hahnemann Medical College	1	0	1	1	–	–	–	11,000	400
Harvard University – Massachusetts General Hospital	–	–	6	6	–	10,000	60,000	–	–
– Robert B. Brigham	20	20	4	4	20,000	–	43,000	100,000	40,000
University of Hawaii	–	–	–	–	–	–	–	–	–
Howard University	–	–	1	0	–	–	–	15,000	–
University of Illinois	1	0	–	–	–	–	–	–	–
Indiana University	–	–	–	–	–	–	–	–	–
University of Iowa	1	1	1	1	–	–	–	10,000(a)	10,000(a)
Johns Hopkins University	5	1	5	5	–	–	55,000	10,000	–
Kansas University	–	–	–	–	–	–	–	–	–
University of Kentucky	–	–	1	1	–	8,000	–	–	–
Loma Linda University	–	–	–	–	–	–	–	–	–
Louisiana State University	–	–	–	–	–	–	–	–	–
Louisiana State University at Shreveport	–	–	–	–	–	–	–	–	–
University of Louisville	–	–	5	0	–	–	–	–	–
Loyola University at Chicago	–	–	1	0	–	–	–	–	–
University of Maryland	–	–	1	1	–	–	5,000(a)	5,000(a)	–
University of Massachusetts	–	–	–	–	–	–	–	–	–
Mayo Graduate School of Medicine	–	–	10	6	–	–	–	90,000	–
Meharry Medical College	–	–	–	–	–	–	–	–	–
University of Miami (Florida)	5	5	5	5	–	–	19,000	20,000	–
University of Michigan	–	–	1	1	–	10,100	41,483	–	–
Michigan State University	–	–	–	–	–	–	–	–	–
University of Minnesota	–	–	9	9	–	–	20,000(a)	20,000(a)	20,000(a)
University of Mississippi	–	–	–	–	–	–	–	–	–
University of Missouri (Columbia)	–	–	–	–	–	–	–	–	–
University of Missouri (Kansas City)	–	–	–	–	–	–	–	–	–

EXHIBIT IV-1
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MEDICAL SCHOOL	RESIDENCIES		FELLOWSHIPS		SOURCE OF SUPPORT				
					ARTHRITIS FOUNDATION				
	OFFERED	FILLED	OFFERED	FILLED	(NATIONAL)	(LOCAL)	NIH	RESIDENCY PROGRAM	OTHER
University of Missouri (Kansas City)	-	-	-	-	-	-	-	-	-
University of Nebraska	-	-	-	-	-	-	-	-	-
University of Nevada	-	-	-	-	-	-	-	-	-
New Jersey College of Medicine And Dentistry (Newark)	-	-	1	1	-	$ 11,000	-	-	-
New Jersey College of Medicine And Dentistry (Piscataway)	-	-	-	-	-	-	-	-	-
University of New Mexico	5	5	5	2	$ 10,200	8,000	$ 54,000	$ 32,000	$ 7,500
New York Medical College	-	-	-	-	-	-	-	-	-
New York University	2	3	3	3	10,000	-	30,000	45,000	10,000
University of North Carolina	-	-	-	-	-	-	-	-	-
University of North Dakota	-	-	-	-	-	-	-	-	-
Northeastern University	-	-	3	3	7,500	-	9,900	-	-
Medical College Of Ohio at Toledo	-	-	-	-	-	-	-	-	-
Ohio State University	-	-	-	-	-	-	-	-	-
University of Oklahoma	-	-	-	-	-	-	-	-	-
University of Oregon	-	-	-	-	-	-	-	-	-
University of Pennsylvania	-	-	4	4	-	4,000	-	11,000	63,000
Medical College of Pennsylvania	-	-	-	-	-	-	-	-	-
Pennsylvania State University (Hershey)	-	-	-	-	-	-	-	-	-
University of Pittsburgh	-	-	4	4	-	20,000(a)	-	20,000(a)	-
University of Rochester	-	-	-	-	-	-	-	-	-
St. Louis University	-	-	1	1	-	-	-	-	13,000
Medical University of South Carolina	-	-	1	0	-	-	-	-	-
University of South Dakota	-	-	-	-	-	-	-	-	-
University of Southern California	-	-	6	6	-	48,500	20,000	34,000	-
Southern Illinois University	-	-	-	-	-	-	-	-	-
University of South Florida	-	-	-	-	-	-	-	-	-
Stanford University	1	1	5	5	-	-	8,000	8,000	32,000
State University of New York at Buffalo	1	1	-	-	-	-	-	10,000(a)	-
State University of New York - Downstate Medical Center	-	-	3	3	-	-	-	20,000	15,000
State University of New York at Stony Brook	-	-	-	-	-	-	-	-	-
State University of New York - Upstate Medical Center	-	-	-	-	-	-	-	-	-
Temple University Medical School - Albert Einstein Med. Ctr.	-	-	3	3	-	4,500	-	9,000	11,500
- Temple Univ. Hospital	1	1	1	1	-	3,000	-	8,500	16,000
University of Tennessee	1	1	3	3	-	-	24,000	57,000	-
University of Texas at Galveston	-	-	-	-	-	-	-	-	-
University of Texas at Houston	-	-	-	-	-	-	-	-	-
University of Texas at San Antonio	-	-	1	1	-	-	-	10,000	-
University of Texas Southwestern	-	-	9	9	30,000	12,000	36,500	-	-
Thomas Jefferson University	-	-	-	-	-	-	-	-	4,000
Tufts University	-	-	-	-	-	-	-	-	-
Tulane University	-	-	-	-	-	-	-	-	-
Union University (Albany)	-	-	-	-	-	-	-	-	-
University of Utah	-	-	-	-	-	-	-	-	-
Vanderbilt University	-	-	-	-	-	-	-	-	-
University of Vermont	-	-	1	1	-	10,000	-	-	-
University of Virginia	-	-	3	1	-	-	-	10,000(a)	-
Virginia Commonwealth University	-	-	3	1	-	-	-	10,000	-
Wake Forest University (Bowman Gray)	-	-	-	-	-	-	-	-	-
University of Washington	-	-	3	3	-	-	25,575	-	-
Washington University (St. Louis)	-	-	3	3	-	-	30,000(b)	-	-
Wayne State University	-	-	4	3	-	11,000	-	20,000	13,000
West Virginia University	-	-	-	-	-	-	-	-	-
University of Wisconsin	-	-	1	0	-	13,100	-	10,500	-
Medical College of Wisconsin	1	0	1	0	-	-	-	15,000	-
Yale University	-	-	3	1	-	-	19,000	-	-
Yeshiva University (A. Einstein)	-	-	6	6	22,000	30,000	31,600	13,000	-
TOTAL	48	42	170	153	$130,240	$351,300	$298,975	$394,000	$309,900

(a) Estimates based on reported number of rheumatology residents and fellows.

- The exhibit also lists the medical schools which do not have rheumatology traineeships

- A discussion of the funding of rheumatology traineeships appears later in this chapter.

- Slightly fewer than 60 per cent of the residents and fellows in rheumatology were graduates of American medical schools.

  - This percentage is significantly below the 83 per cent level among nonrheumatology residents completing elective rotation within the field.

Continuing Education Programs In Rheumatology

- Continuing education programs in rheumatology were offered by 45 medical-school-affiliated institutions in 1971.

  - These institutions usually offered one course per year.

  - Median attendance in these programs was 65.

- Local chapters of the Arthritis Foundation and their affiliated societies also offer continuing education programs in rheumatology.

  - However, the number of local chapters and affiliated societies responding to letters of inquiry was not sufficient to permit estimating the magnitude of these programs.

Rheumatology Training In The Allied Health Professions

- Only three of the allied health professional training institutions responding to the survey indicated specific courses in arthritis and connective tissue diseases; however, 88 per cent of the institutions responding indicated that instruction in arthritis and connective tissue diseases forms a significant part of a course or program.

  - Ninety-three per cent of the nursing schools responding offer some instruction in the field.

PROFILE OF PROFESSIONAL TRAINING IN RHEUMATOLOGY (Cont'd)

  - o In the overwhelming majority of nursing institutions, however, the extent of the instruction is limited to two to five classroom-hours, generally as part of a medical-surgical course.

  - o Fewer than 10 per cent plan to increase the course content related to the field.

  - o Students receive specific clinical training in the care of rheumatology patients in less than 5 per cent of the nursing schools.

- Ninety-three per cent of the physical therapy programs responding indicated that they offer instruction in rheumatology.

  - o For the most part, the training consisted of two to six classroom-hours in a medicine or pathology course.

  - o Approximately 15 per cent plan to increase course content related to rheumatology.

  - o In 35 per cent of the programs, the physical therapy students received practical clinical training in the field.

- Ninety-three per cent of the occupational therapy schools responding offer instruction in the care of rheumatology patients.

  - o For the most part, the extent of training is limited to one or two lectures.

  - o Only one school offered specific clinical training in the field.

- Twenty-seven per cent of the graduate schools of social work responding offer instruction in rheumatology.

  - o The available training appears to be limited to one or two lectures.

- Responses from five colleges of podiatry indicate that diseases of the connective tissues are covered in approximately 10 to 20 hours of undergraduate or graduate courses.

- The three colleges of osteophathic medicine that responded do not provide clinical training in rheumatology.

- In the course of the study, no centers of clinical training in rheumatology were identified beyond medical-school-affiliated institutions.

  - While there appear to be a small number of research training positions in institutions which are not affiliated with medical schools, it was determined that the time and costs involved in surveying a representative sample of such insitutions would be prohibitive, and that the results of such a survey probably would contribute very little to the basic findings of this study

THE SETTING FOR TRAINING IN RHEUMATOLOGY

- Of the 108 accredited medical schools in the nation, 79 reported having an organized rheumatology department, unit or section; the remaining 29 reported that they did not.

  - Thus, one out of every four medical schools offers no organized training in rheumatology.

Clinical Facilities

- Of the 65 medical schools answering detailed questionnaires and indicating that they or their affiliates maintain organized units or clinical centers for rheumatology, only 21 maintain special inpatient units.

  - These units have a median size of 20 beds and an 85 per cent average occupancy rate.

  - An average of 17.3 hospital teaching rounds are conducted per month in these units.

- All 65 centers are capable of providing diagnostic and treatment services to ambulatory patients, and 62 centers provide rehabilitation services.

  - On the average, clinics in the institutions hold 2.8 sessions per week, with 29.2 patients per session and 7.6 clinic physicians participating.

  - Fifty-three of the 65 clinics treat pediatric patients.

Funding Of Traineeships

- Approximately $2.5 million were spent in 1971 to support the traineeships discussed in the preceding section and listed in Exhibit IV-1.
  - The table below presents the sources of funding reported by the institutions which maintain organized centers or other units in rheumatology:

Source Of Support	Amount
Arthritis Foundation (national)	$ 138,240
Arthritis Foundation (local)	351,200
National Institutes of Health	788,595
Residency Programs	794,500
Other Sources	389,900
Total	$2,462,435

  - It should be noted that the above total does not include the few training grants not administered through medical schools and their affiliates or the few funds relating to rheumatology which may flow into medical school departments not directly involved in rheumatology.
  - It is also possible that some schools listed traineeship support grants as rheumatology research support, the amount of which is reported below.

- Sixty-eight medical schools anticipated receiving $7,298,523 in support of rheumatology research in 1972.
  - Much of the research money is concentrated in a few institutions with well-developed programs.
    - o The median per institution is $65,000 (as opposed to an average of $107,353).
    - o Eight of the medical schools anticipate receiving 50.1 per cent ($3,660,116) of the funds available for rheumatology research in 1972.

PROFILE OF PROFESSIONAL TRAINING IN RHEUMATOLOGY (Cont'd)

CURRENT AND PROJECTED OUTPUT FROM RHEUMATOLOGY TRAINEESHIPS

- As mentioned earlier, the total number of traineeships filled by physicians in all medical-school-affiliated institutions in 1971 was 141: 42 residencies and 99 fellowships.
  - If the current rate is maintained, 1,080 new rheumatologists will have been trained by 1981, and 2,161 will have been trained by 1991.
  - By 1981, 512 of the currently practicing rheumatologists will have reached retirement age (65), and by 1991, 1,081 of the current practitioners will have reached retirement age.
- If expected retirees are subtracted from expected graduates, the net increase in rheumatologists would be 568 in 1981 and 1,080 in 1991 - an increase over current numbers of approximately 54 per cent.
  - This estimate is high since it does not take into account the substantial number of rheumatology program graduates who subsequently enter other fields of specialization.

CONCLUSIONS

This chapter presents the basic and most important conclusions drawn from this study of professional manpower in rheumatology. First, it outlines the gap between existing professional manpower resources in the field and the health care needs of the nation. Then, it discusses the current and projected need for rheumatologists and the magnitude of the cost to meet the need.

- Rheumatic Diseases Afflict 10 Per Cent Of The Population

  - Approximately 20.3 million individuals suffer from discernible symptoms of some form of rheumatic disease.

  - Although most prevalent among the elderly, more than 12 million victims of rheumatic diseases are under age 65 and more than 3 million are under age 45.

  - In 1969, these diseases caused victims to spend a total of more than 70 million days in bed.

  - Among people normally employed, more than 14 million days were lost from work due to rheumatic diseases.

    o The number of days lost from work does not include the many lost by those who are so disabled that they are no longer employed, nor does it include the days lost by housewives and students.

- Most Victims Of Rheumatic Diseases Are Not Under Medical Care

  - Of the more than 20 million individuals afflicted with rheumatic diseases, well over 12 million are not receiving medical care, even though many of these experience some degree of disability.

  - Since early accurate medical diagnosis and appropriate treatment can often prevent or delay the appearance of advanced symptoms, the potential for unnecessary suffering among those not under treatment is considerable.

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CONCLUSIONS (Cont'd)

- Most Physicians Who Care For Rheumatic Disease Patients Are Not Specifically Trained For The Task

  - Specialists in rheumatology treat only 3.1 per cent of those afflicted with rheumatic diseases.

  - Other specialists and primary care physicians see about 7 million rheumatic disease patients - yet more than 70 per cent of these physicians have little or no formal education in the complexities of distinguishing among various rheumatic diseases and instituting appropriate modern modes of treatment.

- Many Rheumatologists Are Not Effectively Utilized By The Medical Community

  - Many rheumatologists do not have an opportunity to fully utilize their special skills, since other physicians often fail to refer any but their most difficult rheumatic disease patients to rheumatologists.

    - o The very recent official recognition of rheumatology as a subspecialty of internal medicine hopefully will encourage the development of improved patterns of patient referral.

  - As among physicians in general, some who practice rheumatology full time are not most effectively utilized either, since they devote time to tasks which might be performed effectively by allied health professionals.

- Allied Health Professionals Are Not Adequately Utilized

  - The amount of training in rheumatology currently available in educational programs for allied health professionals limits the usefulness of the graduates of such programs in settings where extensive on-the-job training in the specialty cannot be provided.

  - However, despite the somewhat more substantial rheumatologic training offered to podiatrists, none of the individuals or institutions surveyed reported regular utilization of these professionals.

CONCLUSIONS (Cont'd)

- It Appears That The Number Of Rheumatologists Needed Is Approximately Four-And-One-Half Times The Current Supply

  - Using a broad definition of the specialty, it appears that there are only about 2,000 rheumatologists practicing in the United States, and only 85 per cent of these are engaged primarily in treating patients (with the remainder concentrating on education, research and administration).

  - Approximately 9,300 rheumatologists would be required to provide an optimal level of diagnostic and treatment services to those who desire health care for these diseases (eliminating the 42.9 per cent of the rheumatic disease population who report that their symptoms are not severe enough to require medical care or who choose not to utilize medical care).

  - The estimates cited above have been made by CMP on the basis of the findings of a distinguished panel of rheumatologists from the Manpower Study Committee.

    - The panel first estimated the average number of hours needed per year to care for patients with each of the various rheumatic diseases under ideal diagnostic and treatment conditions.

    - The estimate was limited to hours of direct care or consultation by rheumatologists and did not include the significant portion of care which could approximately be delivered by nonrheumatologists.

    - The total number of specialist-hours of care needed was then divided by the annual number of hours which would be worked by a rheumatologist who did nothing but see rheumatic disease patients 50 hours a week.

    - Thus, the various estimates were understated and are conservative.

CONCLUSIONS (Cont'd)

- By 1981, The Need For Rheumatologists Will Exceed The Supply By More Than 8,000

  - Assuming no change in the prevalence of rheumatic diseases, population growth to 1981 would produce a need for 10,560 full-time clinical rheumatologists to provide optimal care to all rheumatic disease patients desiring care.

  - If new rheumatologists are produced at the current rate (assuming they remain in the field) and existing rheumatologists retire at age 65, there will be only 2,500 rheumatologists by 1981.

  - The estimate of the gap between supply and demand is very conservative in that it assumes that all rheumatologists will be engaged full time in patient care, and that there will be no attrition among the existing rheumatologists other than retirement at age 65.

- To Close The Gap Between The Need For Rheumatologists And The Supply By 1981 Would Require An Increase In The Number Of Existing Traineeships By A Factor Of 6.3

  - Assuming no increase in the average cost of a traineeship and continuation of current public and private support, the production of enough rheumatologists to provide optimal care for all the rheumatic disease patients seeking care would require a 630 per cent increase in training capacity and additional training funds in the amount of $11.1 million per year.

  - These estimates are based on conservative assumptions regarding the level of subspecialty care required by rheumatic disease patients and optimal utilization of all rheumatologists in patient care; they do not include traineeships for research or academic physicians.

  - A minimum of 440 new clinical teaching positions would be required to produce the number of rheumatologists needed for the two levels of care described above.

    o This assumes ideal teaching environments and traineeships of only 12 months duration.

Mr. ROGERS. Thank you, Dr. Shulman, for a very helpful statement. Dr. Engleman.

STATEMENT OF DR. EPHRAIM P. ENGLEMAN

Dr. ENGLEMAN. Mr. Chairman, Dr. Carter, other members of the committee, I too am grateful for the opportunity to speak in support of H.R. 14181.

I am a practicing physician with special interests and training in rheumatic disease, a so-called rheumatologist. I am also clinical professor of medicine and head of the rheumatic disease group, University of California, School of Medicine, San Francisco, and former president of the American Rheumatism Association. Thus I speak on behalf of a broad spectrum of practicing physicians and academicians, who are concerned with the health and devastating economic burden of 20 million arthritic patients.

Now, a major provision of your act is the development of research and training centers. It is my purpose to consider with you a definition of such centers as we see them, their objectives, their functional and operational aspects.

First of all a suggested definition of an arthritis center. We would define the arthritis center as a university affiliated outpatient and inpatient facility for patients with arthritis, where exemplary, comprehensive patient care is given and taught, where provision is made for physicians, allied health professionals, and laboratory scientists to collaborate in research.

The objective of the center would be to fill the total needs in arthritis in three relevant areas: education, research, and patient care.

As Dr. Shulman has already indicated, the term "arthritis" refers to some 100 rheumatic diseases which affect all ages. But common to all of these disorders is the fact that improper diagnosis and delay in treatment can result in irreversible crippling and deformities.

These can be prevented, thus, a major educational need is dissemination of knowledge relating to early, accurate diagnosis and early proper treatment. This will certainly be a major role of the center.

There is an educational need to fill the gap between what is known and what is applied, to fill the gap between existing professional manpower and the needs for trained personnel; and to do all of this, we must attract and recruit well qualified physicians.

For this reason, we need a high quality, visible educational program which the center will certainly provide.

How will the centers help fill the need in research? As Dr. Shulman has indicated, there has been significant advancement in our research in rheumatic disease. But there is at present a need, and the time is ripe for a closer working relationship among laboratory scientists, practicing physicians and allied health professionals. The unique functional aspects of the center will make this collaboration possible, and thus enhance clinical research—and I emphasize clinical research—with resulting benefits to the patient.

How will the center fill the needs in patient care? The center's personnel will be such as to provide optimal instruction of undergraduate and postgraduate students, general practitioners and family practi-

tioners in exemplary comprehensive patient care. And what do we mean by exemplary comprehensive patient care?

First of all, we mean early accurate diagnosis which will be taught by the adult or pediatric rheumatologist in attendance.

We mean the prevention of disability which will be implemented by the physical therapist.

We mean optimal physical restoration in which the reconstructive orthopedic surgeon, hand surgeon and occupational therapist will serve vital roles.

We include personal and educational adjustment. A psychiatrist and/or clinical psychologist will focus their attention on the patient's motivation, his attitude toward his disease, and his adherence to prescribed treatment.

And finally, by exemplary, comprehensive patient care, we mean vocational guidance, vocational training and/or placement. A rehabilitation counselor will be one of our staff personnel.

This is the so-called team approach to the treatment of arthritis. Multidisciplinary resources will certainly permit the application of new knowledge.

The concept of the critical mass is fundamental to the arthritis center plan. If the center is too small, it will not have the comprehensive representation of all the disciplines necessary for optimal arthritis study and care.

I have indicated in my written testimony the minimal effective staffing and faculty requirements. These, it is estimated, will serve a population base of around 1 million people.

And now, just a word about the physical requirements of the center. We would hope that there will be provision for protected beds earmarked for the medical and/or orthopedic treatment of arthritis. We are suggesting some 12 to 20 such beds which will be supported by third-party payments.

We would also request two research beds. Support for these will necessarily come from the grant.

We would recommend an extended care facility or so-called midway house which will be contiguous to the center, which will provide for some additional 12 to 20 beds supported by third-party dollars. These beds will be used primarily for rehabilitation.

There should be an outpatient clinic which will make possible some 6,000 outpatient visits per year.

We would strongly endorse an outreach program with roving consultation boards of professional personnel from the center. These will promote professional and public education in the surrounding communities. These will encourage referrals when indicated, into the center, and they will implement the screening, prevention and control program which is planned so well in your act.

We estimate that the average, direct cost of the described center, over and above the patient generated revenue, is in the neighborhood of $600,000.

In conclusion, Mr. Chairman, I would like to make four points, which I think deserve reemphasis. First, implementation of the proposed center program will permit immediate action; second, such action will provide prototypes of the optimal care of the arthritis patients and thus fulfill critical educational requirements; third, such

action will enhance the collaboration of clinical with laboratory research into the causes and cure of arthritis; and fourth, such action will alleviate an ever increasing and devastating financial burden on the American people.

Thank you very much.

[Dr. Engleman's prepared statement follows:]

STATEMENT OF EPHRAIM P. ENGLEMAN, M.D., CLINICAL PROFESSOR OF MEDICINE AND HEAD, RHEUMATIC DISEASE GROUP, UNIVERSITY OF CALIFORNIA SCHOOL OF MEDICINE, SAN FRANCISCO

It is my privilege to present testimony in support of the Arthritis Act (H.R. 14181) I shall focus primarily on the critical needs, functional and operational aspects of the proposed National Arthritis Research and Demonstration Centers (hereinafter referred to as "Centers"), the creation of which is a major objective of H.R. 14181.

My detailed curriculum vitae is enclosed.[1] I am a practicing physician with special interest and training in arthritis or rheumatic diseases—a so-called rheumatologist. I am also a Clinical Professor of Medicine and Head of a Rheumatic Disease Group in a major American Medical School (University of California in San Francisco), President of the Executive Medical Board of the University of California, San Francisco, Hospitals and Clinics, Consultant in arthritis to the San Francisco Veterans' Administration and Army Hospitals, former President of the American Rheumatism Association and former Secretary General of the International League Against Rheumatism. Thus I speak in behalf of a broad spectrum of practicing physicians, academicians and hospital and medical administrators who are concerned chiefly with the health and devastating economic burden of the 20 million arthritic patients in this country and with the early discovery of the cause and cure of arthritis. I also speak with some knowledgeable background in international rheumatology.

The term arthritis actually refers to a group of some 100 rheumatic diseases which affect all ages. Second only to heart disease as the cause of chronic limitation of activity, arthritis causes the greatest suffering for the most people for the longest period of time and at a staggering annual cost of 9 billion dollars. The symptoms of arthritis may be evanescent and recurrent as in gout and bursitis, or they may be chronic as in rheumatoid, osteo and traumatic arthritis. Common to all of these and other arthritis disorders, however, is the fact that improper or delayed diagnosis and treatment usually leads to crippling with serious disability. In many instances the damage to internal organs may be equally disabling. And yet as many as 12 million of the 20 million individuals with arthritis in this country make little or no effort to obtain medical attention! This is a clear indication of the needs for a public educational program in arthritis which will motivate arthritics to seek qualified care, to seek it sooner than they might otherwise, and to stick with it.

Recent advances in the diagnosis and treatment of arthritis have created a wide gap between available knowledge and its application to the patient. Time is indeed ripe for the multi-disciplinary resources which will make possible in-patient and out-patient application of new knowledge, teaching demonstrations of these advances and the integration of these advances into the health delivery systems. Time is also ripe for a closer working relationship than heretofore possible among the basic scientists, the clinicians and allied health personnel. Such laboratory and bed-side collaboration will be critical to future advances in both laboratory and clinical research and in innovative patient care.

Another serious gap is that between existing professional manpower in rheumatology and the health care needs of the nation. Most physicians who care for arthritic patients are not specifically trained for the task. The number of rheumatologists needed is approximately 4½ times the current supply. In some forty of our medical schools there is no rheumatologist; they can provide only inadequate, if any, training in arthritis for their students and house staff. Another 20 medical schools have only one rheumatologist and insufficient resources to conduct at least a facsimile of an educational and research program in arthritis. Allied health professionals are not adequately utilized simply because extensive on-the-job training in arthritis is not available in teaching institutions. Successful fulfill-

[1] Not printed.

ment of the needs for professional education in arthritis will require, among other things, intensive recruitment of those who will care for these patients. Since successful recruitment is partially dependent upon the excellence of the educational program there is need for the kind of built-in appeal that attracts medical students, well qualified physicians and allied health personnel.

It is my conviction that the proposed Center plan will make possible the fulfillment of our requirements in arthritis for professional and public education and for further advances in research. It will also provide prototypes of patient care and services which will be required in the United States if we are to hasten the availability of early diagnosis and optimal treatment and thus prevent the crippling sequelae of arthritis and the ever increasing financial burden of arthritis to our citizens.

On April 1 and 2, 1974 representatives of the American Rheumatism Association section of the Arthritis Foundation and the American Academy of Orthopedic Surgeons met in order to discuss the operational and functional definitions of an Arthritis Research and Demonstration Center. The following recommendations represent the consensus of those discussions.

The Centers should be housed in teaching hospitals where teaching and research staff, students, house staff, domestic and international Fellows will be available. Patient care facilities will be those required for proper diagnosis and comprehensive care. Comprehensive care includes the prevention of disability and provision for optimal physical restoration, personal and educational adjustment and vocational guidance, training and/or placement of patients. Patient education is also a vital part of exemplary treatment and will be directed to his improved motivation and attitude; he will be encouraged to adhere to the prescribed treatment. At the same time, the limitations of treatment and the early symptoms of relapse will be clearly defined, thereby permitting, if necessary, early modification of treatment and prevention of harmful progression of the disease.

The concept of "critical mass" is fundamental to the Arthritis Center Plan because the Center that is too small will not have the comprehensive representation of all the disciplines necessary for optimal arthritis study and care. "Critical mass" applies not only to the over-all size of the Center, but also to each of the three main areas relevant to the total needs in arthritis: patient-care, education and research.

The following represent the considered opinions of the delegates to the April conference in regard to the ideal minimum for successful implementation of an integrated team approach to the arthritis problem within a designated arthritis unit of a teaching hospital: (1) A director, probably a rheumatologist having demonstrated a scholarly and critical understanding of the rheumatic diseases; (2) an associate director, either a scientifically oriented rheumatologist or orthopaedic surgeon, or a Ph. D. researcher in arthritis, capable of exercising Center leadership in the absence of the director; (3) two other full-time staff physicians with rheumatology training and expertise; (4) a staff orthopaedist, experienced and qualified in reconstructive surgery; (5) other medical specialists available as consultants in rehabilitative medicine, hand surgery, pediatrics, neurology, psychiatry, clinical psychology, podiatry, systems analysis and community health; (6) four rheumatology Fellows qualified while in training to participate in research, to be paid from Center Grant funds; (7) house staff and medical students on rotational assignments; (8) a small service and research laboratory comprising 200 to 600 square feet and capable of performing highly specialized procedures, staffed by two technicians trained and experienced in laboratory analyses required in arthritis research, to be financed in part or in whole by the Center grant; (9) a Nurse Coordinator as liaison between patients and professional staff, also a Center grant position; (10) three physical therapists, whose major function would be in the out-patient clinics associated with the Center, and in the extended care facility connected with the Center; (11) a medical social worker; (12) appropriate nurses, nurses aides, and clerical personnel; and (13) other allied health personnel available as consultants to the center, such as occupational therapists, orthotists, rehabilitation counselors, pyschologists, podiatrists and computer technicians.

Protected beds is the key to the successful development of an economically viable Arthritis Center. The number of beds in a minimally sized Arthritis Center is between 12 and 20, or the size of a single nursing unit. This should be a combination of medical and surgical beds, provided that the orthopaedic beds are directly concerned with arthritis. These are patient care beds which will be totally supported by third party payments. Two additional beds are recommended for

clinical research, geographically attached to the arthritis in-patient unit, rather than as part of a General Clinical Research Center bed unit even if such a unit should exist in the hospital housing the arthritis unit. In a large in-patient arthritis unit of up to 80 or more beds, as many as six clinical research beds are recommended. These clinical research beds would have to be supported by a Center Grant since third party payers do not recognize research time on patients as reimbursable.

An extended care facility contiguous to the Center with approximately the same number of beds, with the exception of those used for clinical research, will be valuable medically and economically for optimal utilization of the Center's capabilities and especially to reinforce the rehabilitation regimen. This facility should be third party reimbursed.

An out-patient clinic, or series of out-patient clinics, capable of handling 6,000 patient visits a year, is another essential unit of an Arthritis Center. Easily accessible living facilities near the Center will make possible short-term intensive group and/or individual education and training for patients who do not require hospitalization.

Satellite, or out-reach programs and roving consultation boards composed of professional personnel from the Center will make a significant professional and public educational impact on outlying communities and an expanded population base. Such outreach programs will encourage referrals, when indicated, into the Center; they will also implement the proposed arthritis screening, early detection, prevention and control programs.

The direct costs of such an Arthritis Center over and above what the revenue from its patients would bring in are estimated at $600,000. per Center. Indirect costs will differ from Center to Center, dependent upon the hospital in which the Center is housed.

Ongoing evaluation will be a critical aspect of the Center program. This will require standardization of records with special attention given to implementation of a minimal Standard Data Base for Rheumatic Diseases now in the process of being developed by The American Rheumatism Association. Comparative evaluation of Center performance by external audit in the area of patient care will require on a mandatory basis that all Centers agree to participate in a uniform evaluation of patient disability upon admission and re-evaluation at various stages throughout subsequent years. These data will reflect the effects of Center care on disease activity, functional capacity of the patient, job stability and economic considerations.

With respect to Center performance in the area of training, the evaluation will include a definition of the number of individuals trained in medical, surgical and allied health skills, and their subsequent roles. The research program of the Center will be evaluated not only in terms of quality through peer review, but also with regard to its relevance to the intent of the Center program which is to be directed toward increasing the effectiveness of arthritis preventive and treatment methods.

Information concerning the natural history of arthritis, the causes of spontaneous remissions and other clinical phenomena are poorly understood because of the limited number of arthritis patients currently available for appropriate study and treatment. The above-described standardization of records, utilizing a Minimal Standard Data Base, will make possible storage of arthritis patient data with the aid of national computerization. Rapid retrieval and accumulation of valuable clinical information will inevitably contribute enormously to our knowledge of arthritis.

In conclusion there are at least four points deserving re-emphasis:

1. Implementation of the proposed Center program will permit immediate action.

2. Such action shall permit fulfillment of educational requirements for the optimal care of the arthritic patient.

3. Such action will enhance the collaboration of clinical with laboratory research into the cause and cure of arthritis.

4. Such action will alleviate an ever-increasing and devastating financial burden on the American people.

Mr. ROGERS. Thank you, Dr. Engleman, for a most helpful statement. We are most grateful to you for being here, too.

Dr. SHULMAN. We now proceed, to the research area, Mr. Chairman. First we will hear from Dr. David Howell, professor of medicine, Arthritis Division, University of Miami School of Medicine.

Mr. ROGERS. I am particularly happy to welcome a Floridian here.

STATEMENT OF DR. DAVID S. HOWELL

Dr. HOWELL. Congressman Rogers, Dr. Carter, members of the House Subcommittee on Public Health and Environment, I am David S. Howell, M.D., professor of medicine and chief of the Arthritis Divisions at the University of Miami School of Medicine and the Miami Veterans' Administration Hospital. I am a rheumatologist both by formal training and practice, and a research specialist in the area of cartilage pathophysiology.

My testimony is directed toward an explanation of research in the rheumatic diseases, and how such research best lends itself to a team effort supported through the mechanism of a center grant in which both rheumatologists and orthopedic surgeons would be able to effectively collaborate on a joint project.

Two years ago the Arthritis Foundation convened a special committee of researchers in the fields of rheumatology and orthopedic surgery under the chairmanship of Dr. Lewis Thomas, then dean of Yale University's School of Medicine, and now president of Memorial Sloan-Kettering Cancer Center. I was privileged to serve as a member of that committee. We arrived at a number of recommendations for areas in which an expanded and sustained research effort would be most productive. These areas are detailed in an attached pamphlet, "New Directions in Arthritis Research" [see p. 158], which summarizes the report of the committee.

Our committee's principal recommendations were:

First, to direct research towards identification of a possible viral or other infectious agent as the cause of arthritis.

Second, to pinpoint the involvement of the body's immune system in the arthritis process, a goal regarded by the committee as being attainable within the next 5 years.

Third, to clarify the mechanisms by which inflammation of affected joints occurs.

Next, to broaden the work being undertaken in biomechanical engineering research in regard to the replacement of joints damaged or destroyed by arthritis.

Fifth, to greatly augment the epidemiological studies of the various major forms of arthritis and to seek explanations for the disproportionate sex ratios and racial susceptibility to certain forms of arthritis; and

Finally, to emphasize the study of cartilage in both healthy and diseased joints, with particular attention given to identification of those chemical substances which are involved in the destruction of cartilage, and to a search for other substances that might inhibit or prevent the degeneration of joints.

It is this last area to which I would like to direct my testimony.

Although a great deal of progress has been made in the last decade in studies of cartilage and, specifically, in studies of osteoarthritis,

disease for which you gave very accurate figures on its very large prevalence, the numbers of well-trained investigators working in this field is tragically limited. In one review of research grants in osteoarthritis supported by the NIH in 1970, less than one dozen research programs were found to be supported.

Also based on the huge losses caused by osteoarthritis in terms of both measurable economic factors and immeasurable human suffering, the amount of money invested in research in osteoarthritis at present is abysmally small.

As demonstrated in other diseases, such as polio, measles and viral hepatitis, expenditure of adequate funds for research can result in huge savings in terms of cost for treatment, in reductions of economic losses due to disability, and alleviation of unnecessary suffering.

It is obvious that a breakthrough in knowledge of osteoarthritis and in the development of specific means of preventing the disease's degenerative process could be particularly beneficial in a disease affecting so many people all over the United States, but particularly in Florida where so many have come to retire.

Present knowledge combined with a well-directed, multicenter research program would provide excellent possibilities for major findings in the near future.

The prevalence and national impact of this disease is easily documented: 40.5 million, or 37 of every 100 adult civilians in the United States over the age of 18 have osteoarthritis to some degree when X-rays of the hands and feet are made in a randomized sample of the population.

What is osteoarthritis? It is a slowly developing disease of the joints, characterized by degeneration or breakdown of cartilige. Proliferation of cartilage and bone forms large spurs in association with cystic changes of bone and hardening of bone beneath the cartilage. There is often gradual development of moderate to severe joint pain, stiffness, limitation of motion and eventual crippling when severe. Its symptoms are discernible as early as the second decade of life. In older groups it is an almost universal finding, occurring in up to 95 percent of persons in different series.

What are the economic costs of osteoarthritis? The Social Security Administration reports that arthritis is second only to heart disease in terms of number of workers disabled. Fifteen percent of all disability payments go to arthritis victims, nearly two-thirds of which have osteoarthritis.

What is the present state of knowledge about osteoarthritis? Treatment of osteoarthritis at the present time is symptomatic rather than specific, since the exact cause of osteoarthritis is unknown. Despite the fact, however, that only symptomatic therapy is available, much can be done to help patients afflicted with this disorder if care can be instituted by well-trained physicians, in the milieu of a center, such as proposed in your bill.

Recent research indicates that the body's metabolism, its endocrine system, its growth and sex hormones, and a newly named Somatomedin, may all be implicated in the development of osteoarthritis.

During the past decade, changes in the level of cartilage and bone function have also been shown to be vital in osteoarthritis. Abnormal

biomechanical stresses in cartilage, for example, appear to be important in the initiation of the disease. These abnormal stresses are associated with an activation, formation, and release of digestive enzymes from cartilage cells which cause breakdown of the supporting cartilage tissue, proteoglycans. Breakdown and decreased concentration of this cartilage eventually results in cartilage ulceration, and eventual osteoarthritis.

We can now measure these abnormal biomechanical forces. One technique of measurement is the "Instant Center," based on the concept of joint rotation.

Routine pathologic studies of osteoarthritic cartilage under the microscope now utilize not only ordinary light microscopy, but also more sophisticated and revealing forms of microscopy, including the electron microscope. Loss of cartilage matrix appears as empty halos around cartilage cells. This distribution of cartilage loss is consistent with release of digestive enzymes from in the cell to the area around the cell. Further investigational studies have demonstrated an actual increase in enzyme content of cartilage cells in osteoarthritic cartilage as compared to normal.

Knowledge of these biomechanical and biochemical concepts is helping to a further understanding of the gross and microscopic changes which are observed in osteoarthritis. Although these concepts represent only an hypothesis of cause, they are of value in that they provide reasonable avenues of study for further investigational efforts and direction for specific research efforts.

Studies of the above concepts would be greatly aided by the availability of experimental models that simulate the human disease in cause and pathology. Although experimental techniques that produce changes which simulate certain components of the disease have been available in the past, newer models capable of reproducing osteoarthritis more accurately have not been devised.

Further efforts to develop more sophisticated models which can simulate this disease even more closely both in its cause and its pathology will be of inestimable value in future studies and in ultimately developing the therapeutic measures which will be capable of preventing, retarding, or reversing the disease process.

Our long-term goal is to obtain a striking advance in the clinical management of osteoarthritis based on rationally developed scientific knowledge of the mechanisms of this disease. In order to reach this goal, a detailed understanding of the normal and abnormal structure, function and metabolism of cartilage, bone, synovial lining and synovial fluid structures which represent the specific sites of this disease must be obtained.

Also, the manner in which the regulating mechanisms of joints and their associated areas fail, and how the structure and function of joints become aberrant, must be understood if we are to be able to devise powerful therapeutic modalities to prevent joint deterioration, or to restore the normal state of joint tissues once they are afflicted.

Indeed, in Miami where we have a research center in arthritis, I would like to say we have a small group of rheumatologists and allied orthopedic surgeons who handle annually from our own recent survey about 15,000 patients with arthritis; 12,000 of these patients have osteoarthritis.

We have to treat these patients in a large complex, including 2,300 beds. Our facilities are scattered. We lack paramedical personnel. We have inadequate possible beds devoted to arthritics care and research and we badly need the organized structure which is comprised in your plans in this bill.

Thank you.

[Testimony resumes on p. 170.]

[Dr. Howell's prepared statement and attachment follow:]

STATEMENT OF DR. DAVID S. HOWELL, PROFESSOR OF MEDICINE, AND CHIEF, ARTHRITIS DIVISION, UNIVERSITY OF MIAMI (FLA.) SCHOOL OF MEDICINE, AND VETERANS ADMINISTRATION HOSPITAL (MIAMI)

Mr. Chairman and Members of the House Subcommittee on Public Health and Environment, I am David S. Howell, M.D., Professor of Medicine and Chief of the Arthritis Divisions at The University of Miami (Florida) School of Medicine and The Miami Veterans Administration Hospital. I am a Rheumatologist both by formal training and practice, and a research specialist in the area of cartilage pathophysiology.

My testimony is directed toward an explanation of research in the rheumatic diseases, and how such research best lends itself to a team effort supported through the mechanism of a center grant in which both rheumatologists and orthopedic surgeons would be able to effectively collaborate on a joint project.

Two years ago, The Arthritis Foundation convened a special committee of researchers in the fields of rheumatology and orthopaedic surgery under the chairmanship of Dr. Lewis Thomas, then Dean of Yale University's School of Medicine, and now president of Memorial Sloan-Kettering Cancer Center, New York City. I was privileged to serve as a member of that committee. We arrived at a number of recommendations for areas in which an expanded and sustained research effort would be most productive. These areas are detailed in the attached pamphlet, *New Directions in Arthritis Research*, which summarizes the report the committee made to the Foundation.

The committee's principal recommendations were:

(1) to direct research towards identification of a possible viral or other infectious agent as the cause of arthritis;

(2) to pinpoint the involvement of the body's immune system in the arthritis process (a goal regarded by the committee as being attainable within the next five years);

(3) to clarify the mechanisms by which inflammation of affected joints occurs;

(4) to broaden the work being undertaken in biomechanical engineering research in regard to the replacement of joints damaged or destroyed by arthritis;

(5) to greatly augment the epidemiological studies of the various major forms of arthritis to seek explanations for the disproportionate sex ratios and racial susceptibility to certain forms of arthritis; and

(6) to emphasize the study of cartilage in both healthy and diseased joints, with particular attention given to the identification of those chemical substances which are involved in the destruction of cartilage, and to a search for chemical substances that might inhibit or prevent the degeneration of joints.

It is this last area to which I would like to direct my testimony.

Subsequent to the development of the recommendations for future directions of arthritis research by The Thomas Committee, The National Institute of Arthritis, Metabolism and Digestive Diseases (NIAMDD) asked that five position papers be developed by the rheumatology-orthopaedic research community to further illucidate specific arthritis research leads which should be followed. The five areas were Rheumatoid Arthritis, Degenerative Joint Disease (Osteoarthritis), Systemic Lupus Erythematosus (SLE), Biomechanical Engineering, and Connective Tissue Physiology. I was asked to assist in the development of the position paper in this last area. I will combine a discussion of this field with that of osteoarthritis, which is closely associated. Cooperating with me on the paper were three orthopaedic surgeons, Dr. Henry J. Mankin, Chief of Orthopaedic Service, Massachusetts General Hospital; Dr. Melvin Glimcher, Professor of Orthopaedic Surgery, Mass. General; and Dr. Lawrence Rosenberg, Professor of Orthopaedic Surgery, New York University School of Medicine; and a fellow Rheumatologist, Dr. Stephen M. Krane, Professor of Medicine and Head of The Arthritis Unit, Mass. General.

(1) Although a great deal of progress has been made in the last decade in studies of cartilage and, specifically, in studies of osteoarthritis, the numbers of well-trained investigators working in this field is tragically limited. In one review of research grants in osteoarthritis supported by the National Institutes of Health in 1970, less than one dozen research programs were found to be supported.

(2) Based on the huge losses caused by osteoarthritis in terms of both measurable economic factors and immeasurable human suffering, the amount of money invested in research in osteoarthritis at present is abysmally small. As demonstrated in other diseases such as polio, measles, and viral hepatitis, expenditure of adequate funds for research can result in huge savings in terms of cost for treatment, in reductions of economic losses due to disability, and alleviation of unnecessary human suffering.

It is obvious that a breakthrough in knowledge of osteoarthritis and in the development of specific means of interdicting the disease's degenerative process could be particularly beneficial in a disease affecting so many people. Although modern advances in corrective surgery can return many victims of osteoarthritis to a near normal life, those patients desperately need many more therapeutic options open to them than are now available. Advances already made in the field make such a breakthrough feasible.

(3) As I will attempt to indicate in this statement, present knowledge combined with a well-directed, multi-center research program would provide excellent possibilities for major findings in the near future.

(4) The need for a substantially expanded basic and clinical research program in osteoarthritis, the most common of all forms of arthritis, and, according to the Social Security Administration, responsible for nearly twice the amount of disability payments than those paid to victims of rheumatoid arthritis, widely believed to be the most crippling form of this disease, is irrefutable.

(5) The prevalence and national impact of this disease is easily documented:

(a) 40.5 million, or 37 of every 100 adult civilians in the U.S. over the age of 18, have osteoarthritis to some degree when x-rays of the hands and feet are made in a randomized sample of the population.

(b) The incidence of osteoarthritis steadily increases from 4 cases per 100 persons aged 18–24 years, to 85 cases per 100 persons in the 75–79 age group.

(c) Twenty-three percent of Americans with osteoarthritis (9 of every 100 persons—or approximately 9 million adults) experience moderate to severe symptoms of this disease, often with loss of motion in major joints and even complete incapacitation.

(6) What is osteoarthritis? It is a slowly developing disease of the joints, characterized by degeneration or breakdown of cartilage. Proliferation of cartilage and bone forms large spurs in association with systic changes of bone and hardening of bone beneath the cartilage. There is often gradual development of moderate to severe joint pain, stiffness, limitation of motion and eventual crippling when severe. Its symptoms are discernable as early as the second decade of life. In older groups, it is an almost universal finding, occurring in up to 95 percent of persons in different series.

(7) What are the economic costs of osteoarthritis? The Social Security Administration reports that arthritis is second only to heart disease in terms of numbers of workers disabled. Fifteen percent of all disability payments go to arthritis victims, nearly two-thirds of which have osteoarthritis.

(8) What is the present state of knowledge about osteoarthritis? Treatment of osteoarthritis at the present time is symptomatic rather than specific, since the exact cause of osteoarthritis is unknown. Despite the fact, however, that only symptomatic therapy is available, much can be done to help patients afflicted with this disorder, if care can be instituted by well-trained physicians.

(9) Recent research indicates that the body's metabolism, its endocrine system, its growth and sex hormones, and a newly named hormone, Somatomedin, may all be implicated in the development of osteoarthritis. Genetic factors appear to be involved in certain forms of the disease, particularly in osteoarthritis of the fingers.

(10) During the past decade, changes in the level of cartilage and bone function have also been shown to be important in osteoarthritis. Abnormal biomechanical stresses in cartilage, for example, appear to be important in the initiation of the disease. These abnormal stresses are associated with an activation, formation and release of digestive enzymes from cartilage cells which cause breakdown of the supporting cartilage tissue (proteoglycans). Breakdown

and decreased concentration of this cartilage eventually results in cartilage ulceration, and eventual osteoarthritis.

We can now measure these abnormal biomechanical forces. One technique of measurement is the "Instant Center", based on the concept of joint rotation.

Routine pathologic studies of osteoarthritic cartilage under the microscope now utilize not only ordinary light microscopy, but also more sophisticated and revealing forms of microscopy, including the electron microscope. Loss of cartilage matrix appears as empty halos around cartilage cells. This distribution of cartilage loss is consistent with release of digestive enzymes from in the cell to the area around the cell. Further investigational studies have demonstrated an actual increase in enzyme content of cartilage cells in osteoarthritic cartilage as compared to normal.

Knowledge of these biomechanical and biochemical concepts is helping to a further understanding of the gross and microscopic changes which are observed in osteoarthritis. Although these concepts represent only an hypothesis of cause, they are of value in that they provide reasonable avenues of study for further investigational efforts and direction for specific research efforts.

Studies of the above concepts would be greatly aided by the availability of experimental models that simulate the human disease in cause and pathology. Although experimental techniques that produce changes which simulate certain components of the disease have been available in the past, newer models capable of reproducing osteoarthritis more accurately have not been devised. Further efforts to develop more sophisticated models which can simulate this disease even more closely both in its cause and its pathology will be inestimable value in future studies, and, in ultimately developing the therapeutic measures which will be capable of preventing, retarding, or reversing the disease process.

GOALS AND PRIORITIES OF FUTURE CLINICAL AND RESEARCH EFFORTS IN OSTEOARTHRITIS

Our long term goal is to obtain a striking advance in the clinical management of osteoarthritis based on rationally developed scientific knowledge of the mechanisms of this disease. In order to reach this goal, a detailed understanding of the normal and abnormal structure, function and metabolism of cartilage, bone, synovial lining and synovial fluid structures which represent the specific sites of this disease must be obtained.

Also, the manner in which the regulating mechanisms of joints and their associated areas fail, and how the structure and function of joints become aberrant, must be understood if we are to be able to devise powerful therapeutic modalities to prevent joint deterioration, or to restore the normal state of joint tissues once they are afflicted.

Over the past two decades, efforts of industry and academic research institutions in multiple scientific disciplines have brought to the research laboratory powerful new tools and methodologies for accomplishing specific goals leading to the eventual prevention and effective specific treatment of osteoarthritis. These new methods include:

New organ and cell culture methods for connective tissues whereby cartilage can be grown in the test tube. The availability of these techniques allows detailed study of cartilage function and response to various noxious influences. Various genetic effects can also be studied. New hormonal and other factors which must be studied under a host of conditions can be more readily appraised in these systems.

New ultramicro biochemical and morphologic methods to study cartilage cells and cartilage matrix metabolism and structure have been devised. These include techniques whereby extremely small amounts of cartilage tissue can be studied both in experimental animals and in cartilage removed from the human as the result of surgery which has been necessary to remove all or part of a joint as a recommended treatment procedure. More powerful microscopes such as electron microscopes are capable of studying tissue structures at the most fundamental levels.

New immunologic techniques for study of cartilage proteins and antigenic sites which might be involved in cartilage breakdown have been developed.

Methods for assessment on a biochemical basis of sequence of amino acids in proteins of connective tissue have been developed.

The above methods allow us to bring into more detailed view the data required for unraveling pathophysiologic events in connective tissue in osteoarthritis.

Utilizing these methods, research can be directed towards two sharply defined objectives: First, to define the series of biologic events that lead to destruction of articular cartilage and based upon this knowledge, prevent the development of osteoarthritis and retard its progression; and secondly, to learn why lesions of articular cartilage, unlike other tissues, do not heal spontaneously, and to discover methods to induce repair of these lesions.

HIGH PRIORITY STUDY EFFORTS

Detailed knowledge of normal joint biomechanics is essential if we are to determine initiating changes involved in the onset of osteoarthritis. Mathematical models based on known properties of cartilage and subchondral bone should be utilized to correlate joint breakdown with abnormal biomechanical forces. Studies of vast amounts of data so obtained can be readily carried out by appropriate use of computers. Work such as this is already in progress but needs to be greatly expanded.

A delineation of the biochemical structure of cartilage components must be obtained if the interrelationships of cartilage breakdown and digestive enzymes is to be attained.

Characteristics of enzymes that degrade cartilage components must be ascertained. The biologic events that lead to activation, increased production and release of these enzymes from cartilage and synovial lining cells need to be better understood. These enzymes which break down cartilage have to be isolated and characterized. There is an excellent chance that specific chemical inhibitors of these enzymes can now be identified which may be effective in retarding the progression of degenerative joint disease. Several of these enzymes have already been described in normal cartilage. However, there is no information at present as to whether these enzymes are the same ones involved in the degenerative joint disease process. In order to determine this, the enzymes must be isolated in pure form, and characterized as to physical and chemical properties.

One or more laboratories isolating these enzymes could prepare them in sufficient quantity so that the enzymes are available to other laboratories involved in the study of cartilage in normals and in patients with degenerative joint disease. Antibodies to highly purified enzymes could then be prepared to determine which of these enzymes are present in quantity in normal and osteoarthritic cartilage, and to describe the distribution of these enzymes in relationship to the histopathology of the human osteoarthritic lesion.

In other laboratories, the biochemical properties of these enzymes and their specific action on a highly purified cartilage component could be described precisely and in detail, to provide the basis for a systematic search for chemical inhibitors which would be effective in the treatment of degenerative joint disease.

An alternative to selective inhibition of enzymes in the treatment of osteoarthritis is the use of hormones or other substances in which stimulate cartilage to repair, thus negating the breakdown process. One such hormone, somatomedin, has already been identified, but is being studied in only a few laboratories.

The role of collagen and specific enzymes which digest collagen should be evaluated. Collagen is a major component of cartilage tissue and recent studies suggest that its breakdown may be closely related to the osteoarthritic process in some situations.

Joint lubrication studies, particularly with reference to synovial fluid characteristics and its interrelationship with cartilage, will serve to better identify the biomechanical forces related to initiation of degenerative joint disease. Synovial fluid is also important in nutrition of cartilage. Specific studies relative to the mechanisms whereby nutrition reaches cartilage surfaces would serve as an important focal point for possible treatment.

As noted before, the availability of new experimental models would allow a more intensified research effort. A more effective simulation of osteoarthritis must be developed if we are to more closely approximate the changes seen in the spontaneously occurring human disease. The availability of these models will allow more rapid testing of numerous therapeutic agents which can be tried, based on rational results of experimental studies. Use of these models can have a powerful impact on moving ahead to effective findings in the field of study in osteoarthritis.

Epidemiologic studies have been carried out, particularly with relationship of osteoarthritis incidence to age, sex and climate. Further epidemiologic studies related to other variables should be pursued. In particular, genetic studies may

help us to develop leads as to biochemical or enzyme defects predisposing persons to the development of osteoarthritis. Detailed family studies of groupings of osteoarthritic patients should be characterized as to their detailed genetic makeup.

Improved delivery of care to the arthritis patient can also be greatly aided improved patient and professional education programs. As I have attempted to indicate, our present state of the knowledge is such that much can already be done on a symptomatic basis to help patients already afflicted with this disease. Our immediate goal should be the improved delivery of appropriate care and treatment of arthritis patients. This will require appropriate care and treatment of arthritis patients. This will require the use of public education methods to bring the patient to the physician. All too often, the patient deprives himself of effective treatment by virtue of the misunderstanding that "nothing can be done for arthritis." It is an obvious corollary that patients seeking help from the physician will be minimally aided unless intensive professional education, both at the undergraduate and graduate levels, as to appropriate methods of therapy is carried out and made available.

H.R. 14181 can make possible the achievement of improved delivery of health care for the millions of patients afflicted by rheumatic diseases as well as an expanded research effort to unveil the various unknowns in arthritis. Such opportunities do not present themselves that often. When they do, the American public should be aware of them and should be anxious for the scientific community to take advantage of these opportunities.

As the state of the art in the rheumatic diseases is raised to the next stage of development through expanded basic research and an accelerated application of clinical research findings, the institution of a new era of therapy for the arthritis patient will not be far behind. Indeed, breakthroughs in terms of our knowledge of the whys and wherefores of many of the rheumatic diseases seem imminent *IF* research efforts which have already begun can be sustained, *IF* new researchers and research teams can be trained and supported in arthritis centers, and *IF* both groups can be assured of support until their research initiatives can be brought to successful conclusions.

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New Directions in Arthritis Research

A Summary of the Report to The Arthritis Foundation by the

NATIONAL ADVISORY COMMITTEE ON THE FUTURE OF ARTHRITIS RESEARCH

Dr. Lewis Thomas, Chairman

INTRODUCTION

Where has arthritis research been going during the past 25 years? Where should it go over the next five years?

To get answers to these questions, and to set new goals, The Arthritis Foundation in 1972 convened a blue ribbon committee of leading researchers in rheumatology and in orthopedic surgery under the chairmanship of Dr. Lewis Thomas, Dean of Yale University's School of Medicine (who will become President of Memorial Sloan-Kettering Cancer Center in June 1973). This committee has met and deliberated, and reported its recommendations. The Foundation considers these recommendations to be the basis for a new era in arthritis research.

THE COMMITTEE REPORT

The committee said that a breakthrough in rheumatoid arthritis and systemic lupus erythematosus, two of the most crippling and life shortening of the more than 80 arthritis diseases, seems imminent if an expanded research effort in arthritis can be mounted and sustained through general support of clinical centers and laboratories currently engaged in biomedical research.

The Research Committee's report which says that the immediate future in arthritis research is exciting and most promising, contains the following introductory statement:

"Today's therapy for the rheumatic diseases is significantly more powerful and in some respects more effective than that of a decade ago, but it continues to be only partially satisfactory.

"It represents the sort of 'halfway' therapy which medicine is obliged to adopt, as stopgap measures for palliation, when the underlying mechanisms of disease are still unknown.

"It is unlikely that we will be able to develop a genuinely effective treatment either for prevention or cure of the disease in question, until these mechanisms are clearly understood.

"This is the central objective of the lines of research which we recommend for priority consideration by The Arthritis Foundation."

An essential part of this program must be long-term funding of established investigation and an immediate increase of support for promising young scientists.

Such an expanded research program in arthritis will call for three to four times the current level of funding. This amount of additional support can not only be efficiently used now, without waste and with only limited expansion of existing research facilities, but, more importantly, it will serve to bring many of the problems which now confront researchers in the rheumatic diseases to complete resolution within the next decade.

The following is a summary of the principal recommendations.

I. Identification of a possible viral agent as the cause of arthritis.

II. Pinpointing the involvement of the immune system in the chain reaction processes of rheumatoid arthritis.

III. Clarification of the mechanisms of inflammation, the first major manifestation of most forms of arthritis.

IV. Broadening of techniques for joint replacement, by design of joints other than the hip and experimentation with new materials.

V. Epidemiological studies of rheumatoid arthritis, systematic lupus, and osteoarthritis to compare characteristics of arthritis populations to those of non arthritics, and to explain increased mortality rates in people with rheumatoid arthritis.

DISCUSSION OF RECOMMENDATIONS

I. Identification of a possible viral agent as the cause of arthritis. One of the most important lines of further study in arthritis research should be directed towards identification of a possible viral or other infectious agent. Identification of an infectious agent as the cause of arthritis—an infection that might be then treated by means of a newly developed drug or warded off by means of a vaccine—would result in one of the biggest pay-offs in research. It is essential, therefore, immediately to expand the "study of rheumatoid joint material, the use of tissue culture methods, and the application of all the techniques in modern virological research, including viral rescue and identification of neoantigens."

II. Pinpointing the involvement of the immune system in the chain reaction processes of rheumatoid arthritis. Closely allied to the possibility that an infectious agent is involved in arthritis is the now virtual certainty that a malfunction of the immune defense system of the body takes place in the

chain reaction which leads to an arthritic condition. The pinpointing of this involvement should be regarded as a major research goal possible of being attained within the next five years, provided that adequate funding is made available. Major efforts should also be directed at clarifying the precise mechanisms for localization of immune complexes in the kidney and small blood vessels. This knowledge could provide therapeutic opportunities to block the processes of renal and vascular injury and thereby reduce fatalities and body impairment.

III. Clarification of the mechanisms of inflammation—the first major manifestation of the most serious forms of arthritis—could lead to the discovery of chemical substances capable of inhibiting the process. Emphasis should be placed on (a) continued elaboration of the relationships between prostaglandins and cyclic AMP, a new "family of hormones" which may reveal a great deal about inflammation and how to treat it; (b) clarifying the role of corrosive enzymes responsible for destruction of cartilage; and (c) an expanded probing of the inflammatory process in both animal models and tissue culture systems.

IV. Broadening of techniques for joint replacement, by design of joints other than the hip and experimentation with new materials. Recent dramatic successes in total hip replacement must be broadened to other joints—knee, shoulder and elbow in particular. This entails design of replacement joints based on a clear understanding of normal joint mechanics, experimentation in the use of new materials, and development of improved anchorage techniques. As a specific example, the methylmethacrylate cement now used in hip replacements may be replaced by polymers which have a porous undersurface, thereby permitting ingrowth of bone-forming tissue into the implant and insuring permanent anchorage.

V. Epidemiological studies of rheumatoid arthritis, systemic lupus, and osteoarthritis to compare characteristics of arthritis populations to those of non-arthritics, and to explain increased mortality rates in people with rheumatoid arthritis. Epidemiological studies are few and far between in rheumatoid arthritis, both adult and juvenile, in systemic lupus, and in osteoarthritis.

Follow-up studies of rheumatoid case populations have revealed an increased mortality which cannot be attributed to complications of treatment and indicate again the general constitutional effects of this disease. Adults with early rheumatoid arthritis, and children with juvenile rheumatoid, should be followed in research protocols to determine those characteristics which distinguish rheumatoid arthritis patients from persons without arthritis as well as those factors which influence the course and prognosis of rheumatoid arthritis.

Explanation should be sought for the remarkable female to male ratio in systemic lupus—5:1 as an average, increasing to 15:1 during the childbearing ages, and decreasing to about 2:1 among older age groups. And why are Black women three times more susceptible than the White females? In osteoarthritis, factors should be searched for which contribute to this widespread disease, other than age, sex, and occupation. The question remains unanswered as to why two of every five Americans over 65 have moderate to severe osteoarthritis.

BACKGROUND ON RECOMMENDATIONS

I. Infection. Rheumatoid arthritis has long been regarded as an infectious disease. However, after the failure of many attempts to isolate bacteria as a causative factor of arthritis in the early 1920's and 30's, and the failure of ordinary antibiotic therapy to help the disease, interest in the microbiological hypothesis waned. Today, however, the emergence of new findings and new ideas brought into being by a con-

centrated effort in biological research, has once again raised to the forefront the investigation of infection as a major factor in arthritis. This renewed interest in the possible infectious nature of arthritis is attributable to the following five factors:

Factor 1. Rheumatic fever, which used to maim and kill thousands of children annually, chiefly by attacking heart valves, was discovered to be a complication of a simple streptococcal infection. Today, rheumatic fever is a relatively minor problem because the causative agent—a streptococcus—responds to antibiotics. This is a tangible example of the dramatic fruits which basic research can bear, provided that research is properly and adequately nourished.

Factor 2. Chronic infections have been discovered often to result in the appearance of rheumatoid factor, a blood substance believed to be specifically associated with rheumatoid disease.

Factor 3. Today, there is a much better understanding of "slow viruses" that "hide" inside the cells of the body in a dormant state before causing damage.

Factor 4. Animal diseases that resemble human rheumatic diseases and that are known to be associated with infectious agents have recently been discovered. The most striking of these are various forms of arthritis in swine, which are a late consequence of bacterial or mycoplasmic infection; a systemic lupus-like disease developed by a species of New Zealand black mice; and Aleutian mink (a viral) disease.

Factor 5. The unsophisticated techniques used by the previous generation of microbe hunters have been replaced with the marvels of our new age of technology in microbiology research which has attracted a new group of young and talented researchers.

II. Immunity. The immune system, which swings into action each time the body is challenged by a foreign substance, is very complex.

When first discovered, immunity itself was always considered a good thing. This belief is presently undergoing revision. Much as water used to extinguish a fire can itself cause great havoc, the immune system is known occasionally to cause damage.

Recent investigation has shown that the immune system can be divided into two subsystems: cellular immunity and humoral immunity. Both of these play a role in rheumatic diseases.

Cellular Immunity refers to the activity of the immune system associated with various white blood cells, especially the lymphocytes, which also play an important role in arthritic inflammation. There are two types of lymphocytes, the "B" type—so called because they come from bone marrow—and "T" type lymphocytes, which derive from the thymus. Each type manufactures its own "line" of chemical substances which take part in immunological reactions. But current research seems to indicate that one type of lymphocyte makes substances that may be harmful to linings of joints.

Furthermore, there is some evidence that in patients suffering from rheumatoid arthritis and SLE, there is an abnormal rate of transformation of one type of lymphocyte into another. This has been compared to the kind of "blastic" transformation observed in cancer patients.

Though this research is still in its infancy, the Research Committee felt that it holds great promise and should be intensified.

Humoral Immunity refers to the *antibodies* (an antibody is the defense substance made by the immune system when challenged by a foreign invader—referred to as an antigen) which circulate freely in the blood stream.

In the normal sequence of events, antibodies capture the antigen and the resulting aggregates are cleaned away by specialized white blood cells. In some forms of arthritis as well as in some other diseases, however, the cleaning up process does not proceed according to plan, and the anti-

body-antigen aggregates, called "immune complexes," damage the small tubules of the kidney (glomeruli) and small blood vessels. This triggers a whole cascade of irreversible events.

III. Inflammation. Whatever the initial cause or causes of rheumatoid arthritis (many investigators believe it to be the combination of an unusual infectious agent and an abnormality of the immune system), the first and major manifestation is inflammation. Inflammation, like immunity, works normally as a housekeeping function of the body. Arthritic inflammation is characterized by the fact that it becomes self-perpetuating and chronic. The processes that take place once inflammation is under way are starting to be well understood, and as the Research Committee recalled, "much of the current interest in the intricate driving mechanisms of inflammation" are another contribution rheumatology has made to other disciplines.

No way has yet been found to permanently halt arthritis inflammation once it is under way. Two biochemical substances that may contribute to the understanding of inflammation and to its treatment have recently been receiving much attention. They are *prostaglandins* and *cyclic-AMP*; which are seen by many investigators as a "new family of hormones." Both already have been proven to play a role in inflammation and the Research Committee recommended that "Future investigators establish more clearly what role these substances play in mediating tissue injury in rheumatic disease." The Committee also felt that this might lead to novel forms of treatment, even before the causes of the rheumatic diseases have been fully understood.

IV. Artificial Joints. Even though spectacular feats have been achieved by the surgical rehabilitation of hips destroyed by arthritis, the Committee urged that research in biomechanics and biomaterials receive high priority. "The concept of total joint replacement must be broadened to other joints—knees,

shoulder and elbow in particular. This entails design of replacement joints based on a clear understanding of normal joint mechanics, construction of joints from materials properly selected for the purpose and exploration of improved techniques of anchorage to host tissue."

The Research Committee also recommended that new non-injurious methods of implantation be developed. They hoped that methylmethacrylate cement, the "glue" orthopedic surgeons inherited from dentistry, be replaced by "polymers which have a porous undersurface permitting ingrowth of bone-forming tissues into the implant, thereby insuring permanent anchorage."

V. Epidemiology. Whereas some scientists concentrate on what is happening inside a single cell, others are taking a look at all those suffering from rheumatic diseases.

A clear familial pattern has not been established with respect to the arthritic diseases, though there seems to be a high prevalence of connective tissue disease in certainffamilies.

The Committee said, "Unfortunately, few studies of incidence of RA have been performed and when done they have been on relatively small populations. Not only should further studies of the incidence of RA be performed, but the patients with early disease should be followed in a research protocol to determine if factors exist that distinguish these persons from those without arthritis and what factors influence the course and prognosis of rheumatoid arthritis."

As the Committee pointed out, there has not been a study investigating the pattern of juvenile rheumatoid arthritis—a severe disease which affects 250,000 youngsters—and urges that such a study be carried out because it "might offer advantages in a search for etiology (the cause) since degenerative factors are minimal and infectious agent relationships might be easier to interpret."

The Committee also called attention to the "remarkable age, race and sex pattern" of SLE. Over all ages, the female-

to male ratio is greater than five females to one male, but with an especially marked female predominance in the childbearing ages of about 15:1. Curiously, the female-to-male sex ratio in the older ages decreases significantly to about 2:1. Even more mysterious is the increased predisposition of the Black female. She is about three times more susceptible to SLE than the White female in terms of incidence and mortality.

VI. Other Directions. The Research Committee also reviewed the important contributions made by those studying the actual structure of cartilage in both health and disease.

The Research Committee recommended that empahsis be put on the identification of chemical substances (enzymes) involved in breaking down healthy cartilage.

In particular the Committee urged a search for chemical substances that might stop (inhibit) such degenerative processes. This line of research would mainly profit the millions who suffer from osteoarthritis.

Much can also be learned from a study of the mechanical structure of cartilage. The effect of aging on joint structure must also be investigated, as would "further work on lubrication mechanisms of joints."

The Committee further stated that a better understanding of the mechanisms of repair of articular cartilage might facilitate the search for drugs that specifically stimulate such repair.

CONCLUSION

This brief summary version of the report of the Research Committee appointed by The Arthritis Foundation gives an indication of the immense complexity of the subject, and the benefits that would result from the eradication of arthritis.

"A research effort can only be successfully begun and sustained," no matter how well conceived, the Committee pointed out in its conclusion, "with general support for the clinical facilities and laboratories in the institutions that are

engaged in biomedical research. An essential part of this support will be for long-term funding of established investigators, as well as an urgent need to support promising young scientists.

"This intensive and multi-faceted effort will be expensive." But as the Committee pointed out, our increased effort for at least the next decade, could be efficiently used without waste; and "would bring many of the problems that now confront us to complete or near complete resolution. The specific therapies and preventive measures for rheumatoid arthritis, SLE, and degenerative joint disease will emerge and begin to take final form as the causes for these diseases are defined fully or in part.

"The immediate future is exciting and most promising. We urge serious consideration and immediate adoption of these recommendations."

The Arthritis Foundation
1212 Avenue of the Americas / New York 10036
1973

APPENDIX

Members of the National Advisory Committee on the Future of Arthritis Research

Lewis Thomas, M.D. (Chairman)*
Dean
Yale University School of Medicine
New Haven, Connecticut

Charles L. Christian, M.D.
Professor of Medicine
Cornell University
College of Medicine
New York, New York

John L. Decker, M.D.
Chief, Arthritis & Rheumatism Branch
National Institute of Arthritis,
Metabolism & Digestive Diseases
Bethesda, Maryland

Denys K. Ford, M.D.
Associate Professor of Medicine
University of British Columbia
Medical School
Vancouver, B. C.
Canada

David Hamerman, M.D.
Professor of Medicine
Albert Einstein College of Medicine
Bronx, New York

David S. Howell, M.D.
Professor of Medicine
University of Miami
School of Medicine
Miami, Florida

Henry G. Kunkel, M.D.
Professor of Medicine
The Rockefeller University
New York, New York

Mart Mannik, M.D.
Professor of Medicine
University of Washington
School of Medicine
Seattle, Washington

Alphonse T. Masi, M.D., Dr. P.H.
Professor of Medicine
University of Tennessee
School of Medicine
Memphis, Tennessee

Carl M. Pearson, M.D.
Professor of Medicine
University of California
Los Angeles
The Center for the Health Sciences
Los Angeles, California

Clement B. Sledge, M.D.
Professor of Orthopedic Surgery
Harvard Medical School
Boston, Massachusetts

Morris Ziff, M.D.
Professor of Internal Medicine
University of Texas
Southwestern Medical School
Dallas, Texas

*In mid-1973, Dr. Thomas is to take office as President and Chief Executive Officer, Memorial Sloan-Kettering Cancer Center, New York, New York.

Mr. ROGERS. Thank you very much, Dr. Howell. We are grateful for your presence here today.

Dr. HOWELL. Thank you.

Dr. SHULMAN. Thank you, Mr. Chairman. To continue on research areas, I would like to present Dr. Carl Pearson, chief of the Rheumatology Unit, University of California at Los Angeles.

Mr. ROGERS. Dr. Pearson, we welcome you.

STATEMENT OF DR. CARL M. PEARSON

Dr. PEARSON. Thank you.

Mr. Chairman, Dr. Carter, Mr. Heinz, it is my privilege to appear before you today, as director of a rheumatology unit.

I am professor of medicine and, as indicated, director of the division of rheumatology at UCLA in Los Angeles.

I am going to talk to you a little bit about research, how far it has gone and how far it needs to go in the next decade, we hope, in order to find solutions to the problems.

I am going to speak especially about rheumatoid arthritis, which is something that, Mr. Chairman, you dwelt upon quite considerably earlier in the afternoon.

Rheumatology today is far different than it was 25 years ago. At that time we knew little more than to categorize the disease and administer as principle.

About that time a number of exciting developments began to occur. There has been an interesting phenomenon called LE cell phenomenon that was described from the Mayo Clinic in 1948 and this with some further studies in evaluation of the antilupus antibody led the entire medical and surgical profession to realize there are autoimmune diseases, diseases in which the body reacts against itself immunologically to destroy itself.

It is our current concept, perhaps with the aid of a virus or some other extrinsic agent, immunity, internally directed allergy or immunity is responsible in rheumatoid arthritis and other similar diseases.

It is really about that same time that Drs. Kendall and Suret and others synthesized cortisone that Dr. Carter has referred to, and that Dr. Philip Hents employed, demonstrated its anti-inflammatory and other activities in patients of rheumatoid arthritis and some of the other activities.

We use cortosteroid very amply, not in rheumatoid arthritis, but in a number of diseases, often devastating, often fatal.

I would like to point out there are a number of cross currents of information occurring in medicine, medical research at the present time.

Not only does research in the field of rheumatology and immunology help itself, but also research in cancer, heart disease, and the like and mechanisms involved in some of those problems come back to us and they derive information from us about their diseases, too. These are important.

Dr. Howell mentioned to you I likewise had the opportunity to serve on this panel under Dr. Louis Thomas in 1972 concerning directions in arthritis research and, Dr. Howell, I would like to have you submit

that for the record if you would kindly do so. [See "New Directions in Arthritis Research," p. 158 this hearing.]

To demonstrate again the excitement, I have just come back from New York on November 20, 21, and 22, where I cochaired a symposium under the New York Academy of Sciences, and the conference was entitled "Mechanisms of Tissue Injury in Rheumatoid Arthritis," and at that conference there were 800 basic scientists, rheumatologists, clinicians, and paramedical personnel present, as well as representatives of the pharmaceutical industry. And it was a very exciting conference indeed, has still got my head spinning I might say.

The entire medical world, I must say, has been alerted not only by discovery of the LE cell test, but also by the rheumatoid factor and other of these factors circulating in these diseased persons that seem to indicate there is an autoallergic response against some factor or factors in the bodies of these individuals and sufferers. And therefore we are learning more about the mechanisms that are involved in these factors and consequently are learning how to treat them, or just barely learning how to treat them.

Nevertheless, there are some new and interesting ways these can be managed, although these are experimental mechanisms at the present time.

The autoimmune diseases not only encompass rheumatology, they encompass a number of other diseases such as multisclerosis, pernicious anemia, and a variety of other diseases and conditions. Thyroiditis and things that do not concern us in our particular field, but I demonstrate this is a large field. This has actually led us to an understanding of this entire new area.

Before 1948, in general, immunology was concerned with immunology of bacteria and viruses and the like, and they knew nothing about autoimmunity as it is known at this present time. Cancer researchers have to deal with this problem all the time, because there is immunity against cancer. Surgeons must deal with this problem because there is rejection of homographs, such as kidney grafts and so on, which is helping us to learn more about patients we deal with.

We, in turn, are helping them by learning more about the fundamental mechanisms that we study.

So, therefore, it appears to me this is an exciting field. This is a field that needs a great deal of added support from the point of view of research, and I can think of no better way this can be achieved than by establishing centers that deal in this regard.

Thank you.

[Dr. Pearson's prepared statement follows:]

STATEMENT OF DR. CARL M. PEARSON, PROFESSOR OF MEDICINE, AND DIRECTOR, DIVISION OF RHEUMATOLOGY, UNIVERSITY OF CALIFORNIA AT LOS ANGELES SCHOOL OF MEDICINE

Mr. Chairman and members of the House Subcommittee on Public Health and Environment, my name is Dr. Carl M. Pearson. I am Professor of Medicine, and Director, Division of Rheumatology, University of California at Los Angeles School of Medicine.

Rheumatology today is far different than it was 20 years ago. We are now a sophisticated field with much more to offer the patient therapeutically, and we are in a much more exciting stage of development of our understanding of the basic disease mechanisms with which we deal. In 1974, research has gone to the more basic or fundamental mechanisms of disease, rather than merely de-

scribing and classifying the disease condition and attempting to treat it as skillfully as possible with the few tools that the Rheumatologist and other physicians had available to them in 1948 and before.

There are constant cross currents of exchange of information between our field and many others, especially basic departments of Immunology, as well as the new specialty of Clinical Immunology.

Clinical Immunology has developed at a phenomenal rate during the past 25 years. Prior to 1948, immunology, the study of the body's defense against foreign invaders as well as its reaction to allergies, was the sole domain of specialists in Infectious diseases in Departments of Basic Science. The most well known specialist in this field was Dr. Louis Pasteur, who observed reactions in both animals and persons to the injection of antigens (foreign proteins) and various micro-organisms.

In 1948, Dr. Hargraves and his associates at the Mayo Clinic made a unique discovery. They found a strange type of cell, subsequently to be called the LE cell, which was present in the bone marrow (and later found in the peripheral circulation) in many patients with the disease we now call systemic lupus erythematosus (SLE). The meaning of this finding was not immediately clear, but it became clearer when, about 1951, again in the field of Rheumatology, some peculiar circulating antibodies were found in the blood serum of most patients with rheumatoid arthritis. Soon thereafter other Rheumatologists, conducting research on what causes the LE cell to form, found another factor in the blood serum which is an antibody to the chromosomal material (DNA) which is now termed antinuclear antibody (ANA). Subsequent studies, again by Rheumatologists, have now demonstrated a large variety of different antibodies against a person's own tissues, as well as an entire family of different antibodies against DNA, in rheumatoid arthritis, and against various other tissues in other conditions related to auto-immunity (auto-allergy or cell allergy) such as antibodies against kidney tissue, hyroid tissue, lung tissue, liver, against red blood cells, etc.

Such observations alerted the entire medical world to the fact that many of the diseases that are dealt with on a daily basis by doctors are caused by abnormal or aberrant immune reactions against the body's own tissues and cells, whether they be normal or slightly altered in form, such as following contact with a virus, a drug (for example, Pronestyl, which is used for treating heart irregularities), etc.

By this time, much of medicine and medical research began to focus on these unusual reactions, and it is now reasonably clear that, perhaps in conjunction with some viruses or medication-induced, either immediate allergy (antibody response) or delayed hypersensitivity (lymphocyte response, as I have indicated in some of my answers to questions) came to be recognized as causing a number of disease states in humans.

Thus, it was really the field of Rheumatology some 25 years ago that stimulated all of the feverish activity that is going on today in every discipline in medicine and surgery in order to try to explain the disease processes in those and other fields. These discoveries in Rheumatology and by Rheumatologists were the starting points for the establishment of a new clinical field of investigation entitled Clinical Immunology which has now been established in parallel with Divisions of Rheumatology in a number of medical schools throughout the world.

The auto-immune diseases, about which a great deal has been written and much intensive research is underway, could include, in addition to those disorders in our own field that I have already alluded to, perhaps multiple sclerosis, certain types of inflammatory eye disease (endogenous uveitis), thyroiditis, a disease which afflicts and lowers the blood platelets (which are important in blood clotting), pernicious anemia, ulcerative colitis and certain other bowel diseases, myasthenia gravis (a disease in which body muscles become weak), polymyositis (another condition in which muscles become weak), etc.

Furthermore, it is now known that resistance to cancer and some leukemias, as well as susceptibility to those conditions, are under some measure of control of the immune response. Cancer researchers are currently working very energetically to determine the nature of these resistance factors and, therefore, to try and heighten the level of immune resistance so as to control cancer growth.

In a similar type of study certain types of heart disease called myocarditis may occur after coronary heart attack or after an injury to the heart muscle.

Such reactions have been attributed to allergic responses against heart muscle (so-called Dressler's syndrome), and these can be treated successfully with corticosteroids. Furthermore, the involvement of the heart muscle and the heart valves after rheumatic fever (which is caused by streptococcal infection), is also an allergic response against the individual's own heart muscle. We now know, for instance, also that the rash that occurs in simple or regular measles (rubeola) is not directly caused by the measles virus itself but rather by an allergic reaction to the measles virus 10 to 14 days after it invades the body.

Furthermore, scientists in organ transplantation, such as in kidney transplants, heart transplants, etc., have come to realize that immune responses of both antibody and delayed types are responsible for the failures of those operations when, later on, the organ undergoes what is called "graft rejection". Thus, the nature of the match between the recipient of the graft and the donor must be matched very closely in order for the graft to be successful, and these matches are undertaken by immunologic matching tests in the laboratory.

Much has been learned in the field of Immunology, as well as in Rheumatology and cancer immunity, etc., that can be applied to one or another discipline. Hence, not only did this entire flurry of activity begin by the observations of Rheumatologists, but also some research in our field has provided clues or answers in other fields. The reverse can also be said so that, for instance, cancer researchers have provided us information about blocking antibodies (antibodies which do not allow other antibodies to perform their normal functions of tumor resistance), and many other examples of similar types of studies could be cited.

Mr. ROGERS. Thank you, Dr. Pearson.

Dr. SHULMAN. Mr. Chairman, we are now going to turn to the important area of orthopedic surgery.

The first discusser is Dr. William Donaldson, professor of orthopedic surgery at Pittsburgh, and presently president-elect of the American Academy of Orthopedic Surgeons.

Mr. ROGERS. We welcome you.

Mr. HEINZ. I might say, Mr. Chairman, I am pleased to welcome the most distinguished gentleman. I am glad you are with us.

STATEMENT OF DR. WILLIAM F. DONALDSON

Dr. DONALDSON. Thank you, Mr. Chairman.

I am Dr. William F. Donaldson, first vice president, president elect, of the American Academy of Orthopedic Surgeons and Academy composed of over 6,000 orthopedic surgeons across the Nation. I am clinical professor of orthopedic surgery at the School of Medicine, University of Pittsburgh.

It is a pleasure to appear before you and your committee today and provide information relative to the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974.

With me in making this presentation on behalf of orthopedic surgery are Dr. Harlan Amstutz, professor and chairman of the Division of Orthopaedic Surgery at the University of California at Los Angeles, and Dr. Clement Sledge, professor of orthopedic surgery at Harvard and chief of orthopedic surgery at the Robert Breck Brigham and Peter Bent Brigham Hospitals in Boston.

Orthopedic surgery is that discipline of medicine concerned with the study, prevention, treatment and rehabilitation of disease and injuries that afflict the musculoskeletal system. The orthopedist is responsible for the care of persons who sustain trauma, develop diseases or present with deformities of bones, joints, ligaments, tendons, and nerves. It is because of this specific concern that we are vitally involved in the management of the patient with arthritis.

In partnership with the rheumatologists, we form the basic medical team for the evaluation, treatment and rehabilitation of patients suffering with arthritis. These patients require a team approach if they are to receive the best medicine has to offer.

In recent years the closer cooperation between the rheumatologist and the orthopedist in the management of these patients has significantly advanced. The responsibility for this improvement has occurred in no small part because of the directed activities of the Arthritis Foundation with its American Rheumatism Association and our American Academy of Orthopedic Surgeons. As an example of this, on April 1 and 2 of this year, a workshop was conducted to define the meaning of an "arthritis center." It was jointly sponsored by the NIAMDD, the Arthritis Foundation, and the American Academy of Orthopedic Surgeons.

As a result of this workshop, both disciplines have a clear definition of their roles in such a project. Both are more acutely aware of each other's specific and interrelated needs in the areas of research, education and patient care. This workshop developed specific information needed to implement the recommendations contained in the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974 under consideration today.

We enthusiastically concur with the recommendations contained in the "arthritis plan." The creation of the position of associate director in the NIAMDD has our full support. The proposed arthritis screening, early detection, prevention, and control programs have the potential for significantly reducing morbidity associated with arthritis. The establishment of arthritis research and training centers will provide the means through which major inroads can be made upon these diseases that are responsible for such major disability among the citizens of our Nation.

It must be clearly stated that the purpose of the development of these centers is not to take over the care of all persons with arthritis, but rather to provide a critical mass of people, physicians, other medical scientists, biomedical engineers and allied health personnel, necessary to mount a significant attack on this most serious health problem.

We are particularly appreciative of the inclusion of a specific section in the act establishing an intramural program on orthopedic research within the NIAMDD. This should result in the development of leadership and significant research in joint implants and other research in the musculoskeletal field. It will provide coordination to the efforts in bioengineering, particularly as they relate to orthopedics.

The Arthritis Prevention, Treatment, and Rehabilitation Act of 1974 as proposed should provide the means to accomplish this.

At the present time there is an alarming shortage of rheumatologists, of orthopedists specifically trained in the management of patients with arthritis, of physicians exposed either in medical school or in postgraduate residency or fellowship or through continuing education to the modern day care of the patient with arthritis, particularly rheumatoid arthritis.

The number of adequately and specifically trained allied health personnel is manifestly inadequate. Therefore, one prong of this attack on arthritis must be the development of teachers and educational programs. In the area of research my rheumatological col-

leagues have spoken to their specific needs. I have asked Dr. Amstutz to present information concerning the current status and the future needs in joint replacement. Dr. Clement Sledge will review other areas of research and discuss the educational requirements in the field of orthopedics as they relate to the patient with arthritis. He will present an outline of the critical mass of personnel necessary to develop this prong of the arthritis attack.

Third, within such a center there must be a sufficient number of patients congregated to accomplish these first two goals, education and research.

We visualize the centers as being an administrative organization within which one can develop and refine new techniques, new drugs, new implants and new operative procedures applicable to the patient with arthritis. Because of the teaching that will occur within such a center, the results of these efforts will be readily available to the medical community at large either through educational programs conducted within the center, or in the outreach satellite clinics, or through continuing medical education programs, refresher courses or by the provision of a broader educational experience in the field of arthritis to medical students, residents in family practice, internal medicine and orthopedic surgery.

Orthopedic surgery enthusiastically supports your efforts as exemplified in the provisions of this act.

Mr. ROGERS. Thank you, Dr. Donaldson.

STATEMENT OF DR. HARLAN C. AMSTUTZ

Dr. AMSTUTZ. I am Harlan Amstutz.

Mr. ROGERS. Welcome.

Dr. AMSTUTZ. As indicated, I am professor of orthopedic surgery and chief of the division of orthopedic surgery, University of California at Los Angeles School of Medicine.

I am here with my colleagues who strongly support the National Arthritis Act introduced into the House of Representatives by 125 Congressmen.

I have been asked by the Academy to present to this committee a report on recent progress in the area of biomechanical engineering, especially in regard to total joint replacement, which has had a significance for arthritis patients comparable to the discovery of cortisone in 1949.

Approximately 135,000 total hip joint replacements have been performed in the past 2 years.

Mr. ROGERS. Excuse me. Is that 135,000?

Dr. AMSTUTZ. Yes. Replacement of the joint is required by arthritis of any type, or there is a failure of previous surgical treatment for arthritis.

The primary advantages of total joint replacement are the elimination of pain, the restoration of joint function, and the attendant low morbidity. Because of pain relief achieved, these patients rapidly regain muscle control and strength to their preoperative level and with rehabilitative programs, additional activity and functional improvement can be achieved. The first successful hip replacement came from England in the 1960's. Despite dramatic successes

from hip joint replacement, significant complication rates have been reported. These complications are of considerable concern since hip replacement has become the primary operation for hip disease even in younger adults.

In recent years, the concept and principles of excising both sides of a diseased joint and replacing it with an artificial bearing have been applied to other joints with varying but encouraging degrees of success. The clinical results to date are not as dramatic or effective as hip replacement although relief from pain at least initially has been accomplished in most instances. For example, the relief of stiffness and improved function has been disappointing from knee joint replacement due to the complexity of knee motion and stability.

Total shoulder endoprosthesis is on the horizon for patients suffering from destructive arthritis or rheumatoid disease of the shoulder joint, particularly types of fractures involving the humerus and scapula, and/or malignant tumors in the humerus, but present designs are grossly inadequate because of difficulty of fixation and shoulder instability.

Ankle, elbow, finger and thumb prosthetic joints are in various stages of experimental clinical trial.

As the senior citizen population increases, so does the number of individuals within this group whose function is impaired or limited by arthritis. Not all of these suffer such severe pain or loss of function as to need surgery, yet because the disease is degenerative, millions of people suffer its ultimate course and effects of pain and total joint destruction.

Although more than 100,000 hip and knee implants were sold last year in the United States, it is too early to determine whether a plateau in the number of implanted prostheses has been reached; but even if the population of aged arthritic patients stabilizes, increased successes with hip replacements will certainly encourage their use in younger patients who have limited joint function.

The population of young people who have received joint replacements is growing. The increased stresses which this group applies to the replacements will result in new problems of prosthesis durability, structural integrity, and wear characteristics.

The prospect of rehabilitating those not able to work toward a level of near-normal physical function and independence is a reasonable goal and even to gain full employment. It is within the reach of our technology. With the exception of the hip joints and that on a short term basis, present reconstructive procedures are not satisfactory at restoring anatomy and physiology for the joint to such an extent as to permit job performance which demands either heavy activity, lifting, or full weight bearing for the working day.

Additional research, suitably organized and completed, is needed to improve existing surgical techniques as well as to expand the function and life expectancy of the implants. These research areas are outlined in the appendix which I submit.

To carry out the vital patient related problems, a control group of patients is needed such as could be accomplished in arthritic centers. Unfortunately, few of the needed research study areas involving implantation and study of materials in vivo can be accomplished with animal research.

Total joint replacement research must be an interdisciplinary effort bringing together the skills and experience of clinicians, pathologists, engineers, and materials scientists to define problem areas and develop specific projects to study them.

Although some of these individual steps in the development of implant design could possibly be performed in an institution without all the resources, the effectiveness of such a program would be minimal without continuous interplay and testing of ideas. This integration can occur only in an organization which provides the disciplines and the facilities needed to investigate problems relevant to the whole design and implantation.

One very important additional ingredient to effective establishment of nationwide research and treatment programs would be to establish an intramural program for orthopedic surgery at the National Institutes of Health, and to expand the number and role of existing bioengineering centers.

I certainly wish to thank you for your interest and support in these important areas.

[Dr. Amstutz' prepared statement and appendix follow:]

STATEMENT OF DR. HARLAN C. AMSTUTZ, IN BEHALF OF AMERICAN ACADEMY OF ORTHOPEDIC SURGEONS

Mr. Chairman and Members of the Public Health and Environment Subcommittee: I am Doctor Harlan C. Amstutz, Professor of Orthopedic Surgery, and Chief of the Divisions of Orthopedic Surgery, University of California at Los Angeles School of Medicine.

I am here together with two of my colleagues from the American Academy of Orthopedic Surgeons, Dr. William F. Donaldson, and Dr. Clement B. Sledge, to support the National Arthritis Act, introduced into the House of Representatives by 125 Congressmen.

I have been asked by the Academy to present to this committee a report on recent progress in the area of biomechanical engineering, especially in regard to total joint replacement, which has had a significance for arthritis patients comparable to the discovery of cortisone in 1949.

Approximately 135,000 total hip joint replacements have been performed in the past two years. Replacement of the joint is required when both surfaces of the joint are destroyed or impaired by arthritis of any type, or there is a failure of previous surgical treatment for arthritis.

The primary advantage of total joint replacement are the elimination of pain, the restoration of joint function, and the attendant low morbidity. Because of pain relief achieved, these patients rapidly regain muscle control and strength to their preoperative level and with rehabilitative programs, additional activity and functional improvement can be achieved. The first successful hip replacement came from England in the 1960's. While the first patients treated were in the older age group, gradually the age limit has been lowered. Despite dramatic successes from hip joint replacement, significant complication rates have been reported. These complications are of considerable concern since hip replacement has become the primary operation for hip disease even in younger adults, even when successful hip joint replacements are not sufficiently durable to permit a laboring man to return to work. In recent years, the concept and principles of excising both sides of a diseased joint and replacing it with an artificial bearing have been applied to other joints with varying but encouraging degrees of success. The clinical results to date are not as dramatic or effective as hip replacement although relief from pain at least initially has been accomplished in most instances. For example, relief of stiffness and improved function has been disappointing from knee joint replacement which began in the late 1960's. This is due to the complexity of knee motion and stability.

Total shoulder endoprosthesis is on the horizon for patients suffering from destructive arthritis or rheumatoid disease of the shoulder joint, particularly types of fractures involving the humerus and scapula, and/or malignant tumors

in the humerus, but present designs are grossly inadequate because of difficulty of fixation and shoulder instability.

Ankle, elbow, finger and thumb prosthetic joints are in various stages of clinical trial.

SIGNIFICANCE

The 1961 U.S. Public Health Service Report on Arthritis estimated that 16,804,000 non-institutionalized persons in the United States suffer some form of rheumatism or arthritis. The November 1973 Arthritis Foundation Fact Sheet reported that 50 million people have some form of arthritis of whom 20 million are seriously affected so as to require medical help and 3½ million are severely or totally disabled.

The social and economic suffering also is emphasized by these two reports. The 1961 estimate indicates that rheumatic diseases account for the loss of 150 million work days annually and result in 1.5 billion dollars in lost wages. The 1973 Fact Sheet indicates 3.5 billion dollars are lost in wages, and 2.5 billion dollars in medical care costs.

Few studies are available on the results of rehabilitating the seriously disabled persons with polyarthritis. Most groups studied have been small and it is difficult to separate early and acute disease which may be medically treatable from advance disease with mechanically unsound joints which are permanently damaged and which require surgical treatment.

As the senior citizen population increases, so does the number of individuals within this group whose function is impaired or limited by arthritis. Not all of these suffer such severe pain or loss of function as to need surgery, yet because the disease is degenerative, millions of people suffer its ultimate course and effects of pain and total joint destruction.

More than 100,000 hip and knee implants were sold last year in the United States. It is too early to determine whether a plateau in number of implanted prostheses has been reached, but even if the population of aged arthritic patients stabilizes, increased success with hip replacements will certainly encourage their use in younger patients who have limited joint function.

The population of young people who have received joint replacements is growing. The increased stresses which this group applies to the total joint replacements will result in new problems of prosthesis durability, structural integrity, and wear characteristics.

The prospect of rehabilitating those not able to work towards a level of near-normal physical function and independence is a reasonable goal and even to gain full employment. It is within the reach of our technology. With the exception of the hip joints and that on a short term basis, present reconstructive procedures are not satisfactory at restoring anatomy and physiology for the joint to such an extent as to permit job performance which demands either heavy activity, lifting, or full weight bearing for the working day.

Additional research, suitably organized and completed is needed to improve existing surgical techniques as well as to expand the function and life expectancy of implants. This is outlined in the appendix.

To carry out the vital patient related problems, a control group of patients is needed such as could be accomplished in arthritic centers. Unfortunately, few of the needed research study areas involving implantation and study of materials in vivo can be accomplished with animal research.

Total joint replacement research must be an interdisciplinary effort bringing together the skills and experience of clinicians, pathologists, materials engineers, mechanical engineers and electrical engineers to define problem areas and develop specific projects to study them.

All disciplines are necessary to observe the progress of a program from its inception through all development stages including facilities and personnel to examine the materials available, study the appropriate design, verify the structural integrity of the device, apply it under controlled clinical conditions to the patient, and finally, maintain careful follow-up procedures to determine the long-term characteristics of the implant.

Although some of these individual steps in the development of implant design could possibly be performed in an institution without all the resources, the effectiveness of such a program would be minimal without continuous interplay and testing of ideas. This integration can occur only in an organization which provides the disciplines and facilities needed to investigate problems relevant to the whole design and implantation.

One very important additional ingredient to effective establishment of nationwide treatment programs would be to establish an intramural program for Orthopedic Surgery at the National Institutes of Health, and to expand the number and role of existing bioengineering centers.

APPENDIX

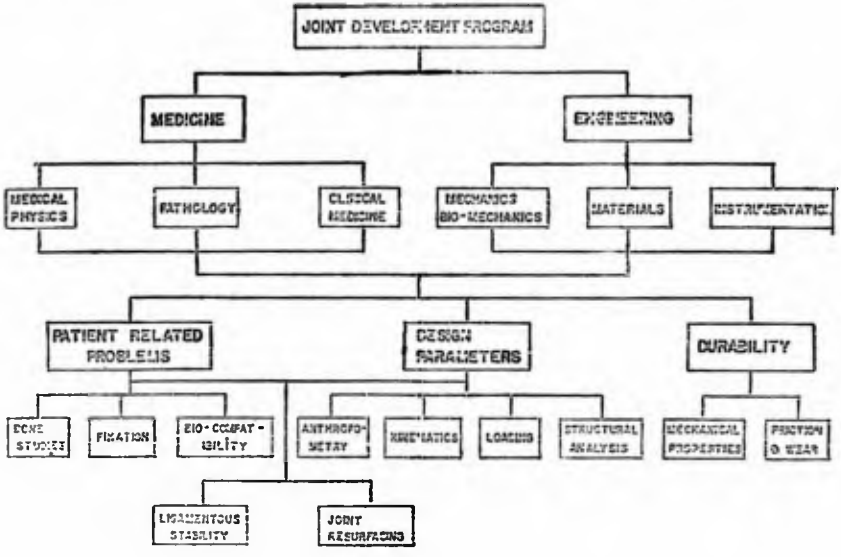
The express objectives of clinical programs and research should be to understand the causative factors and to diminish the complications of sepsis, loosening, subluxation and dislocation, wear and prosthesis breakage, and to apply information gained from clinical experience, biomechanical studies and materials research programs towards the systematic development of new improved joint replacements.

These objectives are outlined on the program organization chart:

1. To study patient-related problems of joint replacements of all types including clinical complications, fixation prosthetic components within the skeleton, biocompatibility of existing and new materials and prosthetic tendon and ligamentous replacement.

2. To gather biomechanical information on human joints necessary to establish design criteria and analysis techniques for new improved joint replacements.

3. To continue experimental materials research projects related to the long-term durability of the prosthesis which involve detailed investigation of the fatigue, fracture and wear properties of prosthetic implant materials.



PROGRAM ORGANIZATION CHART

DEVELOPMENT OF JOINT REPLACEMENTS

I. PATIENT RELATED PROBLEMS

A. Clinical Research

1. Statistical analysis of clinical complications and methods of treatment and prevention.

2. Quantification of biomechanical parameters for clinical evaluation.

B. Biocompatibility

1. Detection and study of metal, acrylic and plastic debris in tissue samples.

2. Examination of tissue-prosthesis interface of removed implants.

3. Animal implantation of bulk and debris samples to screen new materials and to study susceptibility to infection in the presence of wear debris.

C. Skeletal Fixation

1. *In-vivo* bone quality analysis.
2. Biomechanical testing of bone samples obtained from joint replacement patients at time of surgery or autopsy.
3. Study methods of optimizing insertion of fixation materials depending on variable quantity and quality of bone.

D. Resurfacing of Joints

1. Design configurations and fixation mechanisms.

E. Prosthetic Replacement of Ligaments and Tendons

1. Materials selection (thickness, strength, mesh size).
2. Assessment of tissue regrowth in animals (sheath formation, ingrowth into the mesh weave, strength).
3. Fixation (bone-prosthesis attachment, interface strength).
4. Clinical trials after experimental animal program is complete.

II. DESIGN PARAMETERS FOR ARTIFICIAL JOINTS

A. Anthropometric Measurements

1. Direct measurement (replication at surgery, cadaver studies).
2. X-ray analysis.

B. Determination of Joint Loading

1. Development of telemetry systems for *in-vivo* measurement of joint contact forces.
2. Further force plate analysis to correlate with telemetry results.
3. Supporting mathematical analysis.

C. Kinematics and Kinesiology

1. Goniometry studies of joint function.
2. Motion and stability studies of currently available joint replacement prostheses.
3. Development of clinical stability testing apparatus.
4. Pre- and post-operative stability testing of total joint replacement patients.

D. Structural Analysis of Total Hip Replacements

1. Strain gauge instrumentation of prostheses (simulated *in-vitro* loading).
2. Finite element mathematical modelling of bone-prosthesis acrylic or other fixation material composite structures.

III. PROSTHESIS DURABILITY

A. Friction and Wear of Prosthetic Bearing Materials

1. Surface variables (finish, geometry).
2. Test conditions (lubricant, load, speed, specimen sterilization, effects of prior implantation in animals).
3. Compositional variables (metallurgical state, hardness, grain size, crystallinity).
4. New materials and combinations.

Patient Related Problems

A systematic study of the frequency and severity of complications of joint replacement is needed. This has already identified certain modes of failure. Unfortunately, many of the evaluation studies are neither adequately sophisticated nor comprehensive to provide specific information as to the best type of prosthesis to use in specific situations. Emphasis should be placed on programs which do have sufficient numbers for a statistical analysis. Improved methods of evaluation and quantification of biomechanical parameters are needed for all joints.

To assess the biocompatibility of materials, careful histologic, pathologic and immune analysis of tissues from patients are needed. Analysis is needed to determine the effects of corrosion and wear and to study the susceptibility of infection in the presence of debris. Some basic studies can be performed in animals but human material is needed for correlation.

The most urgently needed information from biomaterials studies will include quantitative assessment of bone and its tolerance to biomaterial, and further development of techniques densitometry, ultrasound, etc., additional study and development of fixation materials, both of the filler, i.e., methyl methacrylate, or

porous metals and will include studies of the fracture mechanics of all types of materials particularly in simulated *in vivo* situations. We should have better methods and materials for securing prostheses which lack the problems of heat during polymerization and have better mechanical properties. Extensive investigation of biologically active bonding materials, with attention to careful analysis of the degradation of the materials under the body environment, and the effects of mechanical and physical properties is needed.

Configurations and fixation mechanisms need to be studied in relation to new concepts of resurfacing joints with minimal amount of implanted material. This must include analysis of bone and soft tissue attachment requirements for prosthetic tendons. Development of methods of attaching tendons and ligaments to bone and prosthesis.

Design Parameters for Artificial Joints

Systematic anthropometric studies are necessary to determine accurate dimensional relationships for all joints other than the hip joint. There is need for additional studies on kinematics and kinesiology for all joints. Implantable telemetry systems and further bone plate analysis are needed to assess strength and skeletal fixation.

Studies of more complex physical activities, other than routine walking are needed. This would include stair climbing, various job and sporting activities. Obviously analysis from the latter activities can not practically be derived from instrumented prostheses, because these would be unlikely candidates for joint replacements. Therefore, additional studies could be related to results obtained from units instrumented to replicate or duplicate the more complex forms of human physical activities.

Computer analysis of bone-prosthesis-acrylic and other fixation material composite structures with the latest engineering finite element techniques should be used to examine the structural integrity of existing and proposed joint replacements. These analytical methods should also be used to study parametrically the factors of prosthesis geometry, fixation material thickness and bone quality needed to optimize skeletal fixation.

Prosthesis Durability

Work must continue on developing better bearing materials, polymers, polymer composites, ceramics, and metal combinations. Additional materials include wear and lubrication, the effects of surface finish and sphericity, and the effects of wear on the device itself.

Fatigue testing of implant metals, polymers and bone cements will give essential data needed to understand factors responsible for mechanical failure of implants and insure safe design and fabrication of new prosthetic configurations.

I would also like to mention joint transplantation as a possible mechanism of replacing diseased joints. My present thoughts reflect my belief that there is a much better chance at successful joint reconstruction and subsequent rehabilitation with prosthetic devices. Transplantation poses special and significant problems of immune mechanisms with increased morbidity in addition to those of morphology, and anthropology. In addition, the cost of finding solutions to these problems is likely to be high.

In summary, previous joint replacement has been based on the inexorable needs and demands of the patient and surgeon. Consequently, prostheses have been designed, manufactured and implanted into the patients with few basic biomechanical or kinesiological studies. For truly sophisticated and durable joints, these studies are as essential as the materials research. Both effect design and development and ultimate success.

Mr. ROGERS. Thank you.

Dr. Sledge.

STATEMENT OF DR. CLEMENT B. SLEDGE

Dr. SLEDGE. Yes; thank you very much.

I am Clement B. Sledge, professor of orthopedic surgery at Harvard Medical School and orthopedic surgeon-in-chief at the Peter Bent Brigham Hospital and the Robert B. Brigham Hospital in Boston.

The latter is interesting, from the point of view of the bill, in that it is the only arthritis teaching hospital in this country.

I would like to support your bill wholeheartedly.

With your permission, in view of the hour, I would like to abridge.

Mr. ROGERS. Without objection, your prepared statement will appear after your oral statement [see p. 183].

Dr. SLEDGE. I would like to stress two points only this afternoon. One is the multidisciplinary approach, so evident in the composition of this panel, centered around exemplary care of the arthritic, which has been so successful and which I recommend to you today.

I think it is striking to note this afternoon we have physicians from California, Massachusetts, Ohio, Florida, and a number of other States. And the fact we had to go so far to do this suggests there is not one center in the country at the present time with the personnel to make this presentation.

The patient demands no less these multidisciplinary services than this panel provides.

I think your bill will go a long way toward providing the patient with this sort of approach to his problem.

As has been pointed out by my predecessors, no one of us can do it all. We need pediatricians, occupational therapists, physical therapists, cardiologists—all of us have to pull together on this uniquely human problem.

The administration testimony pointed out the amount of money they are spending in basic research, lab research.

There is no suitable lab model; rheumatoid arthritis occurs only in human beings, therefore the proper study of this disease has to be mankind itself.

The establishment of arthritis centers will enable those of us from different backgrounds to apply our knowledge and expertise to the study of this disease in human beings.

There is a tremendous manpower shortage in orthopedic surgery. There are few orthopedic surgeons who devote themselves to reconstructive surgery of arthritis. We need to overcome this manpower shortage.

Finally, I would point out that in order to provide this interplay between rheumatologist and orthopedic surgeon, we must work together in the same room, taking care of the same patients, providing one another with the intellectual interchange and cross fertilization which can occur only in the format of a center.

Finally, I hope that in just this couple of minutes, I have been able to convey to you some feeling for the victims of this uniquely human disease, whose care today and whose care tomorrow can be greatly advanced through the formation of highly integrated teams of scientists and health care professionals united in a common cause.

If today looks bright for the arthritic due to current capabilities, tomorrow can be even brighter as a result of improved delivery of current capabilities and new efforts in research. Both of these goals can best be met by the establishment of arthritis clinical centers as outlined in the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974. Passage of your bill, sir, will greatly improve the care of millions of Americans as you have brought out in your own comments.

Mr. ROGERS. Thank you, Dr. Sledge, for this helpful statement.

[Dr. Sledge's prepared statement follows:]

STATEMENT OF DR. CLEMENT B. SLEDGE, IN BEHALF OF AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

I am Clement B. Sledge, M.D., Professor of Orthopaedic Surgery at Harvard Medical School and Orthopedic Surgeon-in-Chief at the Peter Bent Brigham Hospital and the Robert B. Brigham Hospital in Boston.

I would like to express my enthusiastic support for the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974 and outline for you some of the ways this bill will improve the lives of millions of Americans through greatly improved research and education in orthopaedic rheumatology.

It is a particular privilege for me to be here today, since I am Surgeon-in-Chief of the only Arthritis Teaching Hospital in this Country. The history of that Hospital is interesting in that it was founded in 1914 to bring together under one roof patients with rheumatoid arthritis, physicians specializing in their care, and scientists carrying out research on joint diseases. It is this multidisciplinary approach, centered around exemplary care of the arthritic, which has been so successful and which I recommend to you today.

I stress the need for arthritis centers on two counts: The nature of rheumatoid arthritis, which involves all ages, all body systems, and all anatomical areas, and the fact that it is a uniquely human disease.

The protean manifestations of rheumatoid arthritis demand the services of rheumatologists, internists, cardiologists, neurologists, pediatricians, orthopaedic surgeons, physical therapists, occupational therapists and rehabilitation nurses. All must have particular knowledge of the disease and its manifestations as well as a knowledge of what the other members of the team have to offer to the patient with a chronic disabling disease. This special kind of knowledge and team work lie outside the usual training format of these specialities. It becomes a speciality in and of itself and must be perpetuated through education of succeeding generations. Medical students and residents in training must be exposed to this integrated team approach to the arthritic, carried out in centers which are large enough to bring together a critical mass of educators in the respective fields involved. These health care professionals can interact most effectively in the format of a center, where all parties have a common interest in taking care of people with arthritis; where the facility is designed to make their care most effective; and where clinicians and investigators can interact at all levels for the benefit of these patients.

In Orthopedic Surgery, the man-power need is acute. We have thousands of surgeons trained in the basic principles of reconstructive surgery but we do not have enough surgeons trained in the application of these techniques to the arthritic with multiple joint involvement, systemic disease, and radically altered functional goals. Total joint replacement is a dramatic recent development which serves to illustrate my point. Of what use is a technically perfect hip replacement if disease in adjacent joints renders the patient immobile, or if cardiac involvement progresses unabated, if involvement of the patients' hands renders them useless for his occupation, or if involvement of the neck leaves him paralyzed?

The team approach, carried out in arthritis centers, can have a powerful educational impact in our health care delivery system. Patients and physicians are anxious for such an approach. A recent survey of the membership of the American Academy of Orthopedic Surgeons revealed that postgraduate courses in arthritis were among the most desired and such courses are consistently oversubscribed. Orthopedic rheumatology and rheumatoid hand surgery are becoming recognized areas of subspecialization. The Arthritis Clinical Center will serve as a focus for such postgraduate education and provide more and more surgeons trained in the reconstructive surgery of arthritis.

In addition, the educational activity of such a center can serve the community-at-large by making all members of the health care delivery team aware of our current treatment capabilities, and, through exemplary care and consultative services, upgrade the level of care for the arthritic in the community and region. It is the team approach, so vital in the successful physical, social and economic rehabilitation of the arthritic, that must be established within the educational matrix of our health care delivery system. Demonstration centers must be established so that medical students, practitioners and allied health professionals can

see this approach in action and learn what can be done today for the arthritic, how to bring today's knowledge to the patient and what must be done in the future to ameliorate the ravages of our most prevalent chronic disability.

The second area I wish to discuss is research. Alexander Pope said that "the proper study of mankind is man." Nowhere in medicine is this more true than in arthritis. Rheumatoid arthritis is unique to humans and there is no suitable animal model available for research. Unlike cancer, which can be studied in the test tube and in animals, even the most fundamental research in arthritis must be carried out in the hospital setting utilizing the tissues normally removed from patients undergoing reconstructive surgery. The mechanisms by which the disease destroys joints can only be studied using these materials and the efficacy of new drugs can be evaluated only by observing the response of patients to such medications. Advances in the management of the arthritic must therefore be made in the setting of a clinical center.

The intellectual cross-fertilization which occurs in such an environment produces maximal advancement in care. The scientist receives continual stimulus from clinical problems and the clinician can immediately apply new therapeutic advances derived from the laboratory. The usual time lag between discovery and application of new therapy is eliminated in a center where communication between disciplines is optimal.

I hope that in these few minutes I have been able to convey to you some feeling for this uniquely human disease whose care today and whose improved care tomorrow can be greatly advanced through the formation of highly integrated teams of scientists and health care professionals united in a common interest.

If today looks bright for the arthritic due to current capabilities tomorrow can be even brighter as a result of improved delivery of current capabilities and new efforts in research. Both of these goals can best be met by the establishment of Arthritis Clinical Centers as outlined in the Arthritis Prevention, Treatment, and Rehabilitation Act of 1974.

Dr. SHULMAN. Thank you.

Now we turn to data gathering, screening programs, and evaluation programs. We have with us Dr. Evelyn Hess, in charge of the arthritis programs at the University of Cincinnati Medical Center.

Mr. ROGERS. Thank you.

Dr. Hess, we are glad to see women also represented.

STATEMENT OF DR. EVELYN V. HESS

Dr. HESS. Oh, we do our best. Mr. Chairman and Dr. Carter, I am a neighbor of yours I guess.

Mr. CARTER. Yes.

Dr. HESS. As you heard, my name is Dr. Hess. I am a professor of medicine and am in charge of the Arthritis Unit at the University of Cincinnati Medical Center, and am chairman of the American Rheumatism Association Computer Committee.

I have been asked by the American Rheumatism Association Section of the Arthritis Foundation to plead the case for those very important sections of H.R. 14181 which are devoted to the support of the development of a common descriptive vocabulary and a standardized data base for the rheumatic diseases. These are section 3(f)(I), and also subsections 438(b)(5) and 438(e)(2).

If we are to successfully and efficiently carry out these charges, this will require of us expert utilization of the most efficient of modern technology.

Now, this would obviously include appropriate use of the computer and all of the science of cybernetics which has contributed so significantly to recent technological advances.

However, I would like to point out to you that in the field of

medicine, in particular, the application of these various computational sciences has been characterized by underachievement, and medicine has seriously lagged behind other professionals in reaping the benefits of computer technology.

The Arthritis Foundation, however, was one of the very first of the professional organizations to recognize this particular deficiency and to attempt to utilize computer and data processing techniques for the benefit of the more than 20 million arthritis patients in the United States.

In June 1971, a rather informal computer committee was formed within the American Rheumatism Association section. This consisted of a small group of biomedical researchers who were concerned with these problems of data handling and exchange.

It pretty quickly became obvious to us, in fact, that what we really needed was to have a common language and many of the members of the ARA were likewise concerned with this problem because they had found difficulties in evaluating the discordant results in various therapeutic studies from many, many different institutions. And so, therefore, between 1971 and 1972 this particular computer committee, worked toward obtaining a unified "minimal standard data base" for the rheumatic diseases. Then we realized that the implications of the data base would be profound and would extend into patient care and teaching as well as research. These various benefits are listed for you in the written testimony and I will not take the time to read them.

We then proceeded to have an American Rheumatism Association workshop on the standard data base. This was held in Chicago in September 1973 and it resulted in an agreement on the common terminology which we should use for rheumatic diseases. This was in fact later published in "Arthritis and Rheumatism," which is the official journal of the ARA, in May 1974, and a reprint of this article is appended and I would like for it to be accepted as testimony.

Mr. ROGERS. Without objection, it will be made a part of the record [see p. 189].

Dr. HESS. Thank you. So this data base then has been circulated to all the members of the American Rheumatism Association, and to many other people throughout the United States. In fact, this particular year, the Computer Committee which is now an official committee of the ARA, is continuing a very active audit and review process of its initial implementation. We are now actively involved in a feasibility study of the National Data Bank Network in Rheumatic Diseases. This network would utilize the standard data base all existing programs in arthritis units. So far there are about nine units which hopefully will have the facility to participate in such a computer data bank during 1974–75.

So you can see, therefore, that the Arthritis Foundation is in an excellent position with the support authorized both in the Senate bill 2854 and in your bill, to help to provide the professional skills and some of the technological facilities required to expedite the formation of a national information system in rheumatic diseases.

How might such a system relate in fact to these various illnesses? Basically there are two needs. Dr. Shulman has referred to these. It has been pointed out by other speakers that epidemiological studies

are very badly needed so screening and detection programs which are essential would utilize this modern technology. I will not take time to list all of the needs which such a program would fulfill.

So I would like to point out to you that the establishment of a national arthritis computer data bank and perhaps a whole series of satellite computers in medical centers which would feed into a central computer bank, would have enormous potential value. I have itemized a few of these.

It could be used to accumulate epidemiological data on the many severe but rarer forms of arthritis in which inadequate numbers of patients are seen in medical centers.

It would permit rapid accumulation of knowledge concerning these and the commoner rheumatic diseases.

It would make feasible drug studies in the presymtomatic or early symptomatic stages.

It would provide a reservoir of information from the many clinical research centers for optimal diagnostic and treatment standards which we would hope to have.

You can see then that these arthritis research and training centers which would be authorized by your bill would have an absolute need for modern data and computer systems.

I would like to mention here, that in terms of funding, the NIH has very small funds available for this type of program and I think that your bill shows enormous foresight in building into it these requirements.

So the efforts of our committee would be to authorize support for the ongoing development and assessment of a common descriptive vocabulary for the rheumatic diseases. We would hope to use all of these modern techniques and we feel that having already done our homework, that we should be in an excellent position to take advantage of all that your bill would provide.

We thank you for your foresight.

[Testimony resumes on p. 199.]

[Dr. Hess' prepared statement and attachment follow:]

STATEMENT OF DR. EVELYN V. HESS, MEMBER, EXECUTIVE COMMITTEE AND CHAIRMAN, COMPUTER COMMITTEE, AMERICAN RHEUMATISM ASSOCIATION

Mr. Chairman and members of the House Subcommittee on Public Health and Environment: My name is Dr. Evelyn V. Hess. I am Professor of Medicine and Director, Arthritis Foundation Clinical Research Center, at the University of Cincinnati Medical Center. I am a member of the Executive Committee of The American Rheumatism Association, and am Chairman of the ARA Computer Committee.

I have been asked by The American Rheumatism Association Section of The Arthritis Foundation to plead the case for those sections of H.R. 14181 devoted to support of the development of a "common descriptive vocabulary" and a standardized database for the rheumatic diseases, namely, Sections 3(f)(1), relative to the work of The National Commission on Arthritis and Related Musculoskeletal Diseases; 438(b)(5), in respect to the application of the standardization of arthritis patient data in screening, detection and control programs; and 438 (e)(2), which calls for the Secretary of the Department of Health, Education and Welfare to "provide for standardization of arthritis patient data and recordkeeping, and for the national collection storage, analysis, retrieval and dissemination of such data in cooperation with the Centers program."

To successfully and efficiently carry out the charges of H.R. 14181, requires the expert utilization of the most efficient of modern technology. Certainly this includes appropriate use of the computer and the science of cybernetics which have contributed so significantly to recent technological advances. In the field of

medicine, however, the application of computational sciences has been characterized by under-achievement. Medicine has seriously lagged behind other professions in reaping the benefits of computer technology.

The Arthritis Foundation, though, was one of the first major professional organizations to recognize this deficiency, and to attempt to utilize computer and data processing techniques for the benefits of the more than 20 million arthritis patients in the U.S.

In June, 1971, an informal "Computer Committee" was formed within the American Rheumatism Association Section of The Arthritis Foundation, consisting of a small group of biomedical researchers concerned with problems of data handling and exchange. It quickly became obvious that computer hardware and software were *less* important than agreement on a Common Descriptive Vocabulary for the Rheumatic Diseases. Other ARA members were likewise concerned with the problem of evaluating discordant results in therapeutic studies from different institutions. There was little way of ascertaining whether patient populations were comparable. The same lack of standardization existed with respect to diagnostic and laboratory procedures in the rheumatic diseases.

During 1971 and 1972, our Computer Committee worked towards obtaining a unified "Minimal Standard Data Base" for the rheumatic diseases. We realized that the implications of such a data base would be profound and would extend into patient care and teaching as well as research. Benefits would include: (1) comparability of clinical studies; (2) compatibility of computer data banks; (3) facilitation of inter-institution collaborative studies; (4) development of an improved framework for teaching in rheumatic diseases; (5) establishment of a data base for clinical decision analysis; (6) a foundation for medical audit in rheumatic diseases; (7) availability of accurate information on the epidemiology of rheumatic diseases; and (8) improved patient care as a result of the above.

An ARA workshop on The Standard Data Base was held in Chicago in September, 1973, which resulted in an agreed upon minimal data base for rheumatic diseases. This was published in Arthritis and Rheumatism, the official journal of the Arthritis Foundation, in May, 1974. A reprint of this article is appended to this statement. This data base has been circulated, therefore, to the 2,200 members of the American Rheumatism Association and to many other interested parties throughout the United States. It is on active trial during this current year, and the Computer Committee, now an official organ of the ARA, is continuing an active audit and review process of its initial implementation.

At present, The Computer Committee is actively involved in a feasibility study of a national data bank network in rheumatic diseases. This network would utilize the standard data base and existing computer programs in Arthritis Centers. At least 9 Centers have the facility to participate in such a computer data bank as of this date. The development of additional pilot programs is being pursued.

It can be seen, therefore, that The Arthritis Foundation is in an excellent position with the support authorized in S. 2854 and H.R. 14181 to help provide the professional skills and some of the technological facilities required to expedite the formation of a national information system in the rheumatic diseases.

I would like now to describe how the standard data base relates to illness. There are basically two aims in screening for chronic illness. One is research (epidemiological investigation) and the other is case finding. However, before any screening program is undertaken, it must first be determined which of these aims are to be fulfilled. If the primary intent is research, then one or more of the following may be objectives:

(1) To determine the prevalence or incidence of the disease;

(2) To determine the natural history of the disease;

(3) To establish the magnitude of the medical problem caused by the disease in terms of disability, morbidity, mortality and costs; or

(4) To study the role of possible causal factors in the disease. If the aim is case finding, then the primary purpose of screening is to detect unrecognized cases of the disease or predict those who are high risk for developing the disease.

Some attempts at chronic disease screening were undertaken during the 1960's by the Federal Government. Retrospectively, the apparent failure of these programs was due to several circumstances.

A principle problem was the lack of any central coordination of screening programs. Although thousands of persons were screened, the information obtained could not be compared because criteria for diagnosis were not the same, the laboratory standardization of tests differed, and necessary follow-up of cases

was impossible. This background pointed to the absolute need for authorization for establishing standards for screening, monitoring the data, and accumulating epidemiological data which would quantify the value of screening in a health care delivery system.

The establishment of a national arthritis computer data bank, perhaps a series of satellite computers in medical centers which would then feed into a central computer bank, would have enormous potential value.

1. It could be used to accumulate epidemiological data on the many severe but rarer forms of arthritis in which inadequate numbers of patients are seen in Medical Centers.

2. It would permit rapid accumulation of knowledge concerning these and the commoner rheumatic diseases.

3. It would make feasible drug studies in the pre-symptomatic or early symptomatic stages.

4. It would serve as a reservoir for providing information derived from clinical research for optimal diagnostic and treatment standards.

As suggested in H.R. 14181, screening activities would be initially conducted on a pilot basis to establish their benefit-cost ratio.

The Arthritis Research and Training Centers authorized by H.R. 14181 would have an absolute need for modern data and computer systems. Such systems would be required:

1. as an audit system to document the impact of the National Arthritis Act funds on the Centers patient care programs;

2. to assess on a quantitative basis, training and education activities;

3. to evaluate basic and applied research programs of the Centers; and

4. to maintain an ongoing analysis of the screening activities referred to above.

The efforts of this Committee to authorize support for the ongoing development and assessment of a common descriptive vocabulary for the rheumatic diseases, using modern computer and data base technology with its great potential, are lauded by The Arthritis Foundation as an absolute necessity for the success of an Arthritis Centers program.

CURRENT COMMENT

A Standard Database for Rheumatic Diseases

The most significant technological advance during the Twentieth Century has been the computer and its exploitation in the science of cybernetics. In medicine, success in applying the computational sciences has been singularly characterized by underachievement. For several reasons, medicine has lagged behind other professions in reaping the benefits of computer technology.

In June 1971 an informal "Computer Committee" was formed within the American Rheumatism Association by a group of investigators concerned with problems of data handling and exchange. It quickly became obvious that computer hardware and software were less important than agreement on a common descriptive vocabulary. Other ARA members were acutely concerned with the problem of evaluating discordant results in therapeutic studies from different institutions, because it was difficult to ascertain whether patient populations were comparable. The same lack of standardization has existed with respect to diagnostic and laboratory procedures in the rheumatic diseases. Definition of many of the common rheumatic diseases, such as juvenile rheumatoid arthritis, scleroderma, systemic lupus erythematosus, and gout, was encouraged by ARA committees formed to define these entities. Lack of definitions for such terms as psychogenic rheumatism and fibrositis are also examples of our poor descriptive vocabulary. If existing computer data banks containing clinical and research information were to continue to grow independently, data could not be compared unless the original observations were made using a common vocabulary.

The Computer Committee convened for 5 work sessions at various ARA meetings, with the enthusiastic approval and help of ARA Presidents John Vaughan, Sidney Stillman, John Decker and Tom Weiss. Interested investigators and clinicians from Rheumatic Disease Centers and Clinics in the United States attended these informal sessions. The importance of the problem, was recognized and it was agreed that efforts be directed towards solving these problems as rapidly as possible. From these discussions, it became apparent that the most immediate need was a minimal standardized database, that is, a list of clinical descriptors and standard units that could be used in whole or in part by all investigators and to which nonstandard descriptors could be added, as required by particular studies. Attempts to define such a vocabulary have been undertaken by individual investigators as required for particular projects, but great variation still exists. During 1971 and 1972 the Computer Committee collected and collated lists and forms used in different institutions throughout the United States and abroad. In September 1972 Drs. James Fries, Evelyn Hess and James Klinenberg merged those forms in common use and drew up a tentative but unified "minimal standard database" for rheumatic diseases.

The implications of such a database would be profound and would extend into patient care and teaching as well as research. Project goals included, a) comparability of clinical studies, b) compatibility of computer data banks, c) facilitation of interinstitution collaborative studies, d) de-

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velopment of a framework for teaching in rheumatic diseases, e) establishment of a database for clinical decision analysis, f) foundation for medical audit in rheumatic diseases, g) availability of accurate information on the epidemiology of rheumatic diseases, h) improved patient care as a result of the above. With the realization that this effort could importantly affect clinical and investigative practices within our subspecialty, it was felt that a broad critical input from many institutions could provide a more acceptable document requiring less radical revision in future years. A proposal to this effect was presented to appropriate committees of the ARA and approved. Necessary funding for a national workshop was appropriated by committees of the Arthritis Foundation. An ARA *Workshop on a Standard Data Base* was held in Chicago on September 15, 16, 1973, with 32 participants representing rheumatic disease practice in the United States in attendance. A great deal of preliminary work on the September 1972 data base model had been accomplished by invited participants prior to the workshop. A very intensive 2-day session provided a preliminary working paper, which had its first public vewing at the thirteenth International Congress of Rheumatology in Kyoto, Japan in October 1973. Suggestions from the many participants at the Congress resulted in further refinements. The present working model appears in this issue of ARTHRITIS AND RHEUMATISM (E. V. Hess).

The list of descriptors, historical, clinical, laboratory and therapeutic is considered to be minimal standard for the initial evaluation of patients presenting with a rheumatic disease. Laboratory procedures include appropriate tests and are to be used selectively. It is hoped that readers of ARTHRITIS AND RHEUMATISM will evaluate this descriptive vocabulary and make use of these descriptors in clinics and offices. Further broad input will assist in future revisions and refinements: precise definition of the listed terms is a future requirement. Workshop participants are currently working on several formats for collecting and recording this information so that it can be used effectively in diagnostic clinics, hospital wards, therapeutic trials, criteria studies and computer analysis. The committee on Rheumatological Practice of the ARA, which has the responsibility for defining standards in Rheumatic diseases for recommendation to professional standards review organizations (PSRO'S) is working closely with the computer committee.

Our goal is the adoption of a minimal standard data base, continually reviewed and broadly defined, which can be used to describe the rheumatic disease patient in the United States and possibly adopted internationally after a suitable trial period in the United States. For these reasons, the computer committee—now an offical organ of the ARA—will continue an active audit and review process in the future. Comments, criticism, and interest in sharing the work are welcomed.

EVELYN V. HESS, MD
University of Cincinnati Medical Center
Cincinnati, Ohio

The following clinical vocabulary evolved through a series of meetings and conferences of the ARA Computer Committee and is designed to serve as a basis for clinical description of the rheumatic disease patient. It is hoped that increased standardization of clinical data, exchangibility of clinical information, and computer-based systems will result. A standard database, as

defined by the committee, is a list of clinical descriptors and units, to be utilized in whole or in part, and to which non-standard descriptors may be added as required. Many formats for presentation of the database in the clinical setting are possible. This full list is intended to represent the initial evaluation of the patient; some formats will be designed to provide for serial observation of these variables. The present document is preliminary, and intended for biennial revision.

General Information
- Date of Examination
- Place of examination
- Examining Physician
- Status (hospital inpatient, ambulatory)
- Patient Identification
  - Name
  - Medical Record Number
  - Street Address
  - City, State, Zip
  - Telephone
  - Birthdate (day–month–year)
  - Occupation
  - Marital Status (single, married, separated, divorced)
  - Sex
  - Ethnic Origin (White, Black, Oriental, Indian, Mexican, Puerto Rican, Other)
  - Social Security Number
- Referral Source (Physician or Institution)
  - Name
  - Street Address
  - City, State, Zip
  - Telephone

Family History: (to include first degree relatives, other blood relatives, spouses. Specify exact relationship of positive responses)
- Rheumatoid Arthritis
- Systemic Lupus
- Spondylitis
- Gout
- Psoriasis

Dates of Onset of Disease
- First sign or symptom of disease
- Diagnosis (date of first correct diagnosis)
- Joints (date of first joint finding)
- Skin (date of first skin finding)
- Renal (date of first renal finding)
- GI Tract (date of first GI Tract finding)
- Neuropsychiatric (date of first neuropsych. finding)
- Muscle (date of first muscle finding)

Past Medical History
- (Allergies, operations, hospitalizations, habits, other)

Review of Systems:

[In this and the following sections, where specific units are not indicated in parentheses, a semi-quantitative standard scale is to be used: 0 = negative, ± = equivocal, 1 = mild, 2 = moderate, 3 = severe. Absence of a notation denotes that the observation was not made. "Past" refers to the period from the first sign or symptom of disease to the present. "Present" denotes signs present at the time of examination or symptoms present within four weeks. Descriptors not listed may be specified.]

General:
- Fatigability
- Fever
- Shaking Chills
- Weight Loss
- Recurrent Infections
- Photosensitivity
- Lymph Node Enlargement

Skin:
- Malar Rash

Psoriasis
- Skin Ulcers, digital
- Nondigital Skin Ulcers (specify)
- Other Rash (specify)
- Abnormal Pigment
- Purpura
- Alopecia (disease or drug)
- Raynaud's Phenomenon
- Change in Skin Texture
- Urticaria

Head and Neck:
- Temporal Head Pain
- Occipital Head Pain
- Other Head Pain
- Dry Eyes
- Conjunctivitis
- Ocular Inflammation, other
- Nasal Complaints
- Ear Complaints
- Oral Mucosal Inflammation or Ulcers

Sore Throat
Dry Mouth
Salivary Gland Enlargement

Cardiopulmonary:
Pleurisy
Dyspnea on Exertion
Cough, persistent
Wheezing
Angina Pectoris
Chest Pain, other
Orthopnea, or PND
Edema, dependent
Edema, other
Hemoptysis

Gastrointestinal:
Anorexia
Dysphagia
Abdominal Pain
Vomiting
Hematemesis or Melena
Jaundice
Diarrhea
Constipation
History of Peptic Ulcer

Genitourinary:
Dysuria
Urethral Discharge
Hematuria
Proteinuria
Renal Stone
Significant Menstrual Abnormality

Hematologic Abnormalities:
Anemia
Leukopenia
Thrombocytopenia

Neuromuscular:
Seizures
Paresthesias
Neuropathy
Muscle Pain
Muscle Weakness
Altered Sensorium

Psychiatric (specify)

Physical Examination—(History scale unless otherwise specified)

Vital Signs:
Height (cm)
Weight (kg)
Blood Pressure–systolic (specify position) (mmHg)
Blood Pressure–diastolic (specify position) (mmHg)
Temperature—(°C)
Respirations (/mm)
Pulse rate (/mm)

Skin:
Telangiectasia
Erythematous Knuckle Pads
Purpura or Ecchymosis
Digital Ulcers, Scars
Ulcerations, other
Sclerodactyly (only)
Acroscleroderma (distal) (only)
Generalized Scleroderma
Calcinosis, dermal
Rash, discoid
Rash, other
Erythema Nodosum
Periungal Erythema
Heliotrope eyelids
Rash, malar
Psoriasis
Alopecia
Keratodermia Blennorrhagica
Nail Pitting
Abnormal Pigmentation
Urticaria
Clubbing
Erythema marginatum
Rash of JRA

Head and Neck:
Fundi, abnormal
Cataract
Conjunctivitis
Episcleral–scleral disease
Uveitis (chronic)
Iritis (acute)
Schirmer test (mm.)
Oral Ulcers
Abnormal Thyroid
Pharyngitis, severe
Pinna, abnormal
Xerostomia
Salivary gland enlargement
Lymphadenopathy, generalized

Chest:
Moist Rales
Dry Rales
Wheezing
Pleural Effusion
Pleural Rubs

Heart:

Enlarged
Systolic Murmur (specify location)
Diastolic Murmur (specify location)
Pericardial rub
Edema, dependent
Edema, other
Arrhythmia
Abnormal P_2

Arteries:
Raynaud's Phenomenon
Temporal artery tenderness
Absent pulses (specify)

Abdomen:
Hepatomegaly
Splenomegaly

Genitalia:
Ulcerations, rashes
Urethral discharge
Rectal/Pelvic abnormality
Pregnancy

Muscles:
Tenderness
Proximal weakness
Distal weakness
Muscle atrophy

Neurologic:
Cranial nerve palsy
Peripheral motor neuropathy
Entrapment neuropathy
Peripheral sensory neuropathy
Psychosis
Personality change

Articular History:
Rapidity of Onset (insidious, abrupt, other)
Overall severity (0–3+)
Number of Involved Joints
Morning stiffness or gelling (hours)
Pattern of nonarticular pain (local, diffuse, radiating)
History of dermal or subcutaneous lumps
Joint swelling
Joint heat/redness
Heel pain, plantar
Heel pain, Achilles
Stress-aggravated joint pain
Nocturnally-aggravated joint pain
Prior skeletal trauma
Course (cyclic, persistent, migratory)
Remissions (none, partial, total)
Response to antirheumatic therapy (none, partial, total)
Response to other therapy (none, partial, total)
ARA Functional Classification, (normal, adequate, limited, incapacitated)

Musculoskeletal Examination:
[Quantitation of abnormalities is performed with the above five-point scale (0,±, 1,2,3). A *minimum* examination consists of observation of each of the listed joint groups, together with characterization of the symmetry and pattern of involvement. A *standard* examination includes observation and separate notation of the two sides of the body. Joints are described by estimation of (1) tenderness or pain on motion, (2) nonbony swelling, (3) loss of motion, and (4) other deformities, for joints in which these may be observed. Small joints of the hands, such as the "right PIP joints," may be considered a unit. Notation should allow reduction of data for each joint group to a single number consistent with the minimum examination. A *complete* examination includes separate observation of individual small joints and may involve additional scales for warmth, erythema, or other variables. (Total description of normal joints is not required.) Notation should allow reduction of data to numbers consistent with the standard examination.]

Joints:
Upper extremity
DIP
PIP
I–P, Thumb
MCP
First carbometacarpal
Wrist
Elbow
Shoulder
Lower extremity
Hip
Knee
Ankle
Sub-talar
Tarsal
MTP
I–P, Great toe
PIP
DIP
First MTP (includes podagra)
Central
Sacroiliac
Lumbar spine
Thoracic spine
Cervical spine

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Other
- Temporomandibular
- Sternoclavicular
- Acromioclavicular
- Costochondral
- Sternomanubrial

Other findings:
- Synovial cysts (eg, Baker's)
- Bursitis (specify)
- Tendon Lesions (specify site) (infection, inflammation, nodule)
- Subcutaneous nodules
- Tophi
- Micrognathia

Functional tests:
- Subjective (working, personal hygiene, etc)
- Objective—
  - Gait (normal, fair, poor, needs assistance, unable to walk)
  - Time to walk 50 feet (sec)
  - Grip strength (mmHg) (right/left)
  - Chest excursion (max cm)
  - Occiput-wall (cm)
  - Chin-chest (cm)
  - Interincisor distance (mm)

Laboratory:

[In contrast to previous sections, it is not intended that each test should be performed in every patient. Laboratory examination should be performed where clinically indicated. This listing provides standard nomenclature and units for the majority of tests which may be employed in a given patient. For the "present" evaluation, where multiple observations are made, record the first valid result. For "past" observations, record the most abnormal value.]

Chemical
- Calcium (mg%)
- Phosphorous (mg%)
- Fasting Blood Glucose (mg%)
- 2-hour Postprandial Glucose (mg%)
- BUN (mg%)
- Uric Acid (mg%)
- Cholesterol (mg%)
- Total Protein (g%)
- Albumin (g%)
- Total Bilirubin (mg%)
- Direct Reacting Bilirubin (mg%)
- Alkaline Phosphatase (mU/ml)
- Lactic Acid dehydrogenase (mU/ml)
- SGOT (mU/ml)
- Sodium (mEq/Liter)
- Potassium (mEq/Liter)
- Chloride (mEq/Liter)
- CO_2 (mEq/Liter)
- Creatinine (mg%)
- SGPT (IU)
- Aldolase (IU)
- Amylase (IU)
- Triglycerides (mg%)
- Creatine Phosphokinase (IU)
- Salicylate level, specify hours after last dose (mg%)
- T4 (Thyroxin) (mg%)
- T3 (mg%)
- Plasma Cortisol (mg%) (specify time)

Hematologic:
- White Blood Count (cells/.001 cu mm)
- Hematocrit (%)
- RBC Count (/.001 cu mm)
- Hemoglobin (g%)
- Differential White Count
  - Neutrophils (%)
  - Bands (%)
  - Lymphocytes (%)
  - Monocytes (%)
  - Eosinophils (%)
  - Basophils (%)
  - Other, undifferentiated (%)
- Description of peripheral smear
- Platelets (/.001 cu mm)
- Reticulocytes (%)
- Sedimentation Rate, Westergren (mm/hr)
- Sedimentation Rate, Wintrobe (mm/hr)
- Prothrombin time (%)
- Partial thromboplastin time (sec)
- Serum Iron (mg%)
- Iron Binding Capacity/Transferrin (mg%)
- Fibrinogen (mg%)
- Haptoglobin (mg%)
- Hemoglobin Electrophoresis (type)
- Guaiac (stool occult blood) (0–3+)

Serology:
- LE Preparation (negative, equivocal, positive)
- ANA (Fluorescent) (titer)
- ANA Pattern (H,P,S,N)
- Anti-DNA (% bound)
- Anti-DNA (titer)
- C3 (mg%)
- CH50 (hemolytic units)
- C4 (mg%)
- Latex Fixation–slide test (+,0)
- Latex Fixation (tube titer)
- SCAT (titer)

- IGA (mg%)
- IGG (mg%)
- IGM (mg%)
- Cryoglobulins (mg%)
- Coombs, Direct (+,0)
- ASO (titer)
- STS (VDRL) (titer)
- FTA (+,0)
- Protein Electrophoresis (specify abnormalities)
- Immunoelectropboresis (paraprotein present, absent)
- Australian Antigen (titer)

Urine:
- pH
- Specific Gravity
- Glucose (0–4+)
- Protein (0–4+)
- Acetone (0–4+)
- RBC/hpf
- WBC/hpf
- Granular casts/hpf
- White cell casts/hpf
- Red cell casts/hpf
- 24-hour urine creatinine (mg/24 hr)
- Creatinine clearance (ml/min)
- 24-hour protein (g/day)
- 24-hour uric acid (on purine free diet) (mg/day)
- 24-hour urinary creatine (mg)
- Urine Immunoelectrophoresis (paraprotein present, absent)

Pulmonary Function:
- Vital capacity (ml)
- 1-second expiratory volume (%VC)
- Total Lung Capacity (ml)
- Diffusing apacity—CO

Cerebrospinal Fluid:
- Opening Pressure (mmH_2O)
- Protein (mg%)
- Glucose (mg%) (simultaneous blood)
- Cells (/cu mm)
- Polymorphonuclear leukocytes (%)

Joint Fluid:
- Joint aspirated (specify)
- Protein (mg%)
- Mucin clot (normal, fair, poor)
- Glucose (mg%) (simultaneous blood)
- WBC (cells/.001 cu mm)
- Polymorphonuclear leukocytes (%)
- Urate crystals (intracellular, extracellular, both)
- Calcium Pyrophosphate Crystals (intracellular, extracellular, both)
- Joint fluid complement (mg%)

Skin tests:
- PPD (specify preparation (mm induration)
- Coccl (mm induration)
- Mumps (mm induration)
- Tricophyton (mm Induration)
- Candida (mm Induration)
- Varidase (streptokinase, streptodornase) (mm erythema)
- DNCB (mm erythema)

Biopsies (specify organ and degree of abnormality)

Cultures: Identify source and organism

Electrocardiogram: (normal, abnormal, specify)

X-rays: Identify region (normal, abnormal, specify)

Therapy

- Salicylate (g/day)

Type of salicylate (plain, buffered, enteric-coated, choline, sodium)
- Antimalarials (mg/day)

Phenylbutazone or oxyphenbutazone (mg/day)
- Colchicine (mg/day)
- Indomethacin (mg/day)
- Chrysotherapy (gold) (total mg)
- Prednisone equivalents (mg/day)

Prednisone dosage schedule (divided daily dose, daily dose, every other day)

Adrenocorticotrophic Hormone (units)

Uric Acid Lowering Drugs:
- Probenecid (Benemid) (g/day)
- Allopurinol (mg/day)
- Sulfinpyrazone (Anturane) (mg/day)

Immunosuppressives:
- Cyclophosphamide (Cytoxan) (mg/day)
- Azathioprine (Imuran) or 6-mercaptopurine (mg/day)
- Chlorambucil (mg/day)
- Methotrexate (mg/week)
- Other immunosuppressive and cytotoxics

Local anti-rheumatic treatment:
- Intraarticular steroid (specify joint)
- Intraarticular, other (specify joint)
- Nonarticular local injection (specify)

Surgery:
- Joint surgery
- Synovectomy (specify joint)
- Reconstructive surgery without prosthesis (specify joint)

Reconstructive surgery with prosthesis (specify joint)
Total joint replacement (specify joint)
Other surgery and special surgery (specify)

Physical and occupational therapies:
Physical measures (heat, cold, paraffin, etc.)
Therapeutic exercises (active, passive)
Appliances and devices (splints, canes, braces, crutches, etc.)

Analgesics (includes Tylenol, Darvon, Talwin, Codeine, Demerol, and others)

Antimicrobial agents
Penicillin
Tetracycline
Sulfa drugs
Isonlazid (INH)

Anticoagulants (specify)

Anticonvulsants (specify)

Antihistamines (specify)

Antihypertensives
Hydralazine (apresoline)
Alpha-methyl dopa (Aldomet) (mg/day)
Other

Cardiac agents
Procaine Amide (Pronestyl) (g/day)
Propranolol (mg/day)
Other

Diuretics (specify)

Gastrointestinal agents (specify)

Hormones (excludes prednisone and other steroids; includes insulin and oral hypoglycemics)
Oral contraceptives

Miscellaneous agents

Psychoactive agents

Suspected drug reaction

Diagnosis:

[Based upon American Rheumatism Association nomenclature and classification of arthritis and rheumatism, 1973, as printed in the *Primer of the Rheumatic Diseases*. Coding developed from the ICDA-8, 1969. Multiple diagnoses are possible.]

I. Polyarthritis of unknown etiology
A. Rheumatoid Arthritis 712.5
B. Juvenile Rheumatold Arthritis 712.0
C. Ankylosing spondylitis 712.4
D. Psoriatic Arthritis 696.0
E. Reiter's Syndrome 136.

II. "Connectlve Tissue Disorders" (acquired)
A. 1. Idiopathic Systemic Lupus Erythematosus 734.I
2. Drug-induced lupus-like syndrome 734.16
B. Scleroderma 734.0
1. Localized (Morphea) 701.0
2. Systemic 734.01
C. Polymyositis and Dermatomyositis 716.0
D. Necrotizing arteritis and other forms of Vasculitis
I. Polyarteritis nodosa 446.0
2. Hypersensitivity angiitis 446.2
3. Wegener's Granulomatosis 446.3
4. Giant cell arteritis, Takayasu type (aortic arch or great vessel) 446.6
5. Cogan's Syndrome 363.9
6. Cranial or temporal arteritis 446.4
7. Polymyalgia Rheumatica 717.90
8. Other 446.9
E. Amyloidosis 276.0
F. Others (unspecified) 734.90

III. Rheumatic Fever 390.

IV. Osteoarthritls (Degenerative Joint Disease) 713.

V. Nonarticular Rheumatism 717.
A. Fibrositis 717.91
B. Intervertebral disc and low back syndromes
1. Disc 725.
2. Other low back 728.7
C. Myositls and myalgia, nonspecific 717.92
D. Tendonitis and peritendonitis, Bursitis 731.9
E. Tenosynovitis 731.91
F. Fasciitis 732.0
G. Carpal tunnel syndrome 357.2
H. Others 733.9

VI. Diseases with whlch arthritis is frequently associated
A. Sarcoidosis 135.
B. Relapsing Polychondritis 729.9
C. Henoch-Schonlein Syndrome 287.0
D. Ulcerative colitis 563.01
E. Regional lleitis 563.0
F. Whipple's Disease 039.0
G. Sjogren's Syndrome 734.91
H. Familial Mediterranean Fever 025.9

VII. Associated with known Infectious agents
A. Bacterial
1. Gonococcus 098.3
2. Meningococcus 036.1
3. Pneumococcus 710.91

4. Streptococcus 038.0
5. Staphylococcus 710.93
6. Salmonella 710.92
7. Brucella 023.0
8. Streptobacillus moniliformis (Haverhill Fever) 026.1
9. Tuberculosis
   a. of spine 015.0
   b. of joints 015.9
10. Syphilis, Treponema pallidum 094.0
11. Yaws, Treponema pertenue 102.6
12. Others 710.99

B. Rickettsial 711.01
C. Viral 711.02
   1. Rubella 056.0
   2. Mumps 072.0
   3. Viral hepatitis 070.0
   4. Others 711.02
D. Fungal 711.03
E. Parasitic 711.04

VIII. Traumatic and/or neurogenic disorders
   A. Traumatic arthritis 714.0
   B. Neuropathic arthropathy (Charcot Joints) 094.0
   C. Shoulder-hand syndrome 358.9
   D. Mechanical (internal) derangement of joints 714.0
   E. Others 714.1

IX. Associated with known biochemical or endocrine abnormalities
   A. Gout 274
      1. Primary 274.0
      2. Secondary 274.1
   B. Chondrocalcinosis articularis (Pseudogout) 718.01
   C. Alkaptonuria (ochronosis) 270.6
   D. Hemophilia 286.0
   E. Sickle cell disease and other hemoglobinopathies 282.5
   F. Agammaglobulinemia (hypogammaglobulinemia) 275.0
   G. Gaucher's disease 272.2
   H. Hyperparathyroidism 252.0
   I. Acromegaly 253.0
   J. Thyroid acropachy 242.2
   K. Hypothyroidism 244.
   L. Scurvy (hypovitaminosis C) 264.
   M. Hyperlipoproteinemia type II (xanthoma tuberosum and tendinosum) 759.6
   N. Fabry's disease (angiokeratoma corporis diffusum or glycolipid lipidosis) 272.2
   O. Hemachromatosis 275.2
   P. Hashimoto's Disease 244.01
   Q. Others 273.0

X. Tumor and tumor-like conditions
   A. Synovioma
      1. Benign 215.
      2. Malignant 171.9
   B. Primary juxtaarticular bone tumors 232.0
   C. Metastatic tumors 170.8
   D. Leukemia 207.9
   E. Multiple myeloma 203.
   F. Waldenstrom's macroglobulinemia 446.3
   G. Benign tumors of the articular tissue 213.9
   H. Others 215.0

XI. Allergy and Drug Reactions
   A. Serum sickness 999.5
   B. Arthritis due to drugs 960.0 (Exclude drug-induced lupus and gout)
   C. Others 960.0

XII. Inherited and congenital disorders
   A. Marfan syndrome 759.8
   B. Homocystinuria 270.8
   C. Ehlers-Danlos syndrome 757.2
   D. Osteogenesis imperfecta 756.6
   E. Pseudoxanthoma elasticum 757.1
   F. Cutis laxa 757.2
   G. Mucopolysaccaridoses (including Hurler's syndrome) 273.8
   H. Arthrogryposis multiplex congenita 755.8
   I. Hypermobility syndromes 723.9
   J. Myositis (or fibrodysplasia) ossificans progressiva 733.2
   K. Tumoral calcinosis 279.0
   L. Werner's syndrome 258.9
   M. Congenital dysplasia of the hip 755.6
   N. Others 756.9

XIII. Miscellaneous Disorders
   A. Pigmented villonodular synovitis and tenosynovitis 731.9
   B. Behcet's syndrome 136.
   C. Erythema nodosum 695.2
   D. Relapsing panniculitis (Weber-Christian Disease) 686.9
   E. Aseptic necrosis of bone 723.5
   F. Juvenile osteochondritis 722.9
   G. Osteochondritis dissecans 722.5
   H. Erythema multiforme (Stevens-Johnson Syndrome) 695.1
   I. Hypertrophic osteoarthropathy 723.1
   J. Multicentric reticulohistiocytosis 279.

K. Disseminated lipogranulomatosis (Farber's disease) 279.
L. Familial lipochrome pigmentary arthritis 709.9
M. Tietze's disease (costochondritis) 729.9
N. Thrombic thrombocytopenic pupura 446.5
O. Primary Raynaud's Phenomenon 734.09
P. Others 787.3

XIV. Undiagnosed
A. Monoarthritis 715.I
B. Polyarthritis 715.
C. Intermittent (palindromic) arthritis 712.2

For the Computer Committee
James F. Fries
Evelyn V. Hess
James Klinenberg

Participants in the
Standard Database Workshop
Chicago, September, 1973

Gene Ball, John Bland, John Canoso, James Cassidy, John Decker, Jack Klippel, Joseph Levinson, Joshua Levy, Michael Lockshin, Alfonse Masi, Thomas Medsger, Allen Meyers, Donald Mitchell, Donald Palmer, Raymond Partridge, Robert Pinals, Robert Ritchie, Jesse Roberts, Naomi Rothfield, Frank Schmid, Lawrence Shulman, Charles Sisk, Sydney Stillman, Robert Swezey, Helen Thompson, Charles Tourtellotte, Stanley Wallace, Max Weiner, and Robert Willkens.

Comments and suggestions are solicited and will be considered for future revisions. Address comments and requests for reprints to Dr. Charles Sisk, The Arthritis Foundation, 1212 Avenue of the Americas, New York 10036.

Mr. ROGERS. Thank you very much.

Dr. SHULMAN. Mr. Chairman, I wonder if you would be kind enough to excuse the three California members of our panel?

Mr. ROGERS. We certainly will.

We apologize for holding you too late.

Dr. SHULMAN. Not at all.

Mr. ROGERS. We appreciate every member of the panel being here. We appreciate your time.

Dr. SHULMAN. Dr. Amstutz tells me he has to go home to put in a joint replacement tomorrow morning, that is, to cure an arthritis patient.

Mr. ROGERS. Thank you very much for your presence. We are very grateful.

Dr. SHULMAN. Now, sir, we have yet to hear from Miss Janice Maynard, who is an important officer of our Allied Health Professionals Section of the Arthritis Foundation.

Mr. ROGERS. Delighted to have you.

STATEMENT OF JANICE MAYNARD

Miss MAYNARD. Thank you.

Mr. ROGERS. Please proceed.

Miss MAYNARD. Mr. Chairman, I am very pleased to be here today to represent both the American Occupational Therapy Association and also my colleagues of the Arthritis Foundation.

I would like to submit my written statement but in an effort to avoid duplication of some of the things that have been said, I will curtail this testimony, but there are a few key items I would like to mention. Particularly the allied health professional is concerned with the prevention treatment, and rehabilitation of those patients suffering from arthritis. They can provide such services as range in motion, muscle strength, ability to perform activities of daily living; and last but not least, work simplification techniques.

Now, as regards the bill H.R. 14181, this would establish a national commission. And we know this commission is to include six officials of the Federal Government, one member of the National Arthritis Metabolism and Digestive Diseases Advisory Council, four members of the general public, and six scientists or physicians. And we would like to go on record as suggesting that one of these commission members represents those allied health professions involved in the arthritis programs.

We fully endorse and support that section of the bill which authorizes the development of arthritis centers for research and training activities.

A 1972 Arthritis Foundation survey of professional manpower in rheumatology showed that there is a serious shortage of occupational therapy personnel specifically trained to assist the patient with arthritis. According to this survey, 93 percent of occupational therapy schools offered classroom instruction in the care of rheumatology patients, but the amount of specific clinical training in this area for the occupational therapist wishing to specialize was very limited, almost nonexistent.

Therefore, we think the arthritis centers to be established by H.R. 14181 should offer clinical affiliations or fellowships for a variety of health personnel, including the nurse, the occupational therapist and physical therapist, and to provide continuing education programs for allied health practitioners in the community and the region.

Further, that we would like to suggest additional funds be earmarked for training grants, for graduate students in the allied health sciences and for special lectureships, workshops, and traineeships for allied health schools which are not directly affiliated with a medical school.

Contrary to something said earlier, we do indeed believe early detection of arthritis, followed by appropriate treatment procedures, can prevent deformity and save years of disability and pain.

I would also like to refer to a missing element in H.R. 14181; namely, financing services for ambulatory and home-care patients. The housewife with osteoarthritis will probably not be seen by an occupational therapist until her condition is exacerbated, requiring hospitalization.

A 1969 survey showed that only 1 of every 85 patients suffering with arthritis ever saw an occupational therapist.

Further, unless the aforementioned housewife's condition gets worse and she receives treatment in the hospital, where it is paid for her, she will not be able to receive treatment, because the arthritis patient receiving services in a nonhospital setting finds few if any third-party payers reimburse her for occupational therapy services. Medicare, for example, will pay for an orthotic technician to construct a brace for a stroke patient in an ambulatory clinic; but will not reimburse a nonhospital based clinic for the services of the occupational therapist in fabricated splints or constructing adaptive devices for the arthritic patient.

As you well know, many volunteer health insurance contracts simply do not cover ambulatory care by physicians, or other health professionals.

We urge you, therefore, to consider the need to provide additional funds for the centers' operational expenses, including staff.

Mr. Chairman, the American Occupational Therapy Association is grateful for this opportunity to support your bill.

I would be pleased to answer any questions.

[Miss Maynard's prepared statement follows:]

STATEMENT OF JANICE MAYNARD, OTR, IN BEHALF OF THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION

Mr. Chairman and Members of the Subcommittee, I am Janice Maynard, OTR, Chief of the Occupational Therapy Department, Union Memorial Hospital, Baltimore. I appreciate this opportunity to represent the American Occupational Therapy Association in support of H.R. 14181, to provide for the development of a long-range plan to advance the national attack on arthritis and related musculoskeletal diseases. The Association represents some 18,000 registered occupational therapists, certified occupational therapy assistants and students.

As a key member of the interdisciplinary health team involved in the prevention, treatment, and rehabilitation of arthritis, the occupational therapist serves these patients in the hospital, office or clinic, home, and even on the job. Services provided by the occupational therapist include evaluation and treatment programs to improve range of motion, muscle strength and the ability to perform activities of daily living; evaluation and construction of orthotic and self-help

adaptive devices; instruction in joint protection and work simplification techniques.

We should like to commend this Subcommittee for scheduling these hearings in the midst of a busy Congressional session with a limited time frame. The magnitude and complexity of the problem—50 million Americans affected by arthritis, the effect on the quality of life for those who live with its pain and disability, and its economic impact on our country—are factors which warrant this special attention. We urge prompt consideration and enactment of this measure.

H.R. 14181 would establish a National Commission on Arthritis to formulate a long-range plan for a national attack on the disease. We note that the 17-member Commission is to include 6 officials of the Federal government, one member from the National Arthritis, Metabolism, and Digestive Diseases Advisory Council, 4 members of the general public, and 6 scientists or physicians. We wish to suggest that one Commission member represent those allied health professions involved in arthritis programs. This specification should be included in Section 3(b). The Commission's recommendations for the effective utilization of our national resources will require the expertise and participation of these other health professionals. Their representation on the National Commission seems appropriate and desirable.

We fully endorse and support that section of the bill which would authorize the development of arthritis centers for research and training activities. These centers would provide a focal point for the interdisciplinary training of all personnel, the physician, nurse, occupational therapist, physical therapist, and social worker. Each has a unique and important role in the treatment of the arthritis patient. Each must understand, appreciate, use and support the particular contribution of the other. The proposed centers offer an ideal setting in which these professionals can interact in support of each other for the benefit of the arthritis patient. The student and the new practitioner should be exposed to this integrated team approach involving educators, researchers, and clinicians.

Arthritis and related musculoskeletal diseases involve not only patients of all ages but also all body systems and anatomic areas, requiring a special breadth and depth of knowledge. A 1972 Arthritis Foundation survey of professional manpower in rheumatology showed that there is a serious shortage of occupational therapy personnel specifically trained to assist the patient with arthritis. According to this survey, 93 percent of occupational therapy schools offered classroom instruction in the care of rheumatology patients, but the amount of specific clinical training in this area for the occupational therapist wishing to specialize was very limited, almost non-existent.

The arthritis centers to be established by H.R. 14181 should offer clinical affiliations or fellowships for a variety of health personnel, including the nurse, the occupational therapist and physical therapist. These centers should provide continuing education programs for allied health practitioners in the community and the region. We also recognize the opportunity for general public education and information programs through these centers.

For the establishment and development of the centers, the bill authorizes a first-year appropriation of $18 million, increasing to $20 and $22 million in subsequent years. It is our understanding that this amount will finance 20 arthritis centers at major medical schools. We should like to suggest that additional funds be earmarked for training grants to graduate students in the allied health sciences and for special lectureships, workshops, and traineeships for allied health schools which are not directly affiliated with a medical school.

We enthusiastically support that section of the bill which authorizes demonstration projects for prevention and control. Early detection of arthritis, followed by appropriate treatment procedures can prevent deformity and save years of disability and pain. One of the challenges for the occupational therapist is to find and identify harmful factors in the individual's behavior and environment and to develop methods whereby the patient may avoid these behavioral patterns or environmental stresses, thus preventing unnecessary disability or deformity.

For example, the woman with osteoarthritis of the knees, who deliberately does her washing in the basement, climbing up and down the stairs because she does not want to get stiff, is only causing further damage—purely through ignorance. Who is going to learn about her habits and redirect her? Probably the occupational therapist who analyzes the demands and effect of activities and uses them as one medium of treatment. The occupational therapist must understand

not only the implications of the patient's disease, the anatomy, kinesiology and potential deformity, but also the patient's way of life, daily life tasks, vocational demands, and recreational needs as well. Only then can a therapist counsel the patient on how best to prevent future deterioration of his or her arthritic condition.

In concluding, I should like to refer to a missing element in H.R. 14181; namely, financing services for ambulatory and home-care patients. The housewife with osteoarthritis will probably not be seen by an occupational therapist until her condition is exacerbated, requiring hospitalization.

This is not a new problem to this Subcommittee, and it may not be appropriate to fund services to patients under the rubric of research and training centers or demonstration grants. But this as a pervasive unsolved problem facing tomorrow's centers and today's patients.

The arthritis patient receiving health services in a nonhospital setting finds that few, if any third-party payors reimburse for occupational therapy services. Medicare, for example, will pay for an orthotic technician to construct a brace for a stroke patient in an ambulatory clinic; but will not reimburse a nonhospital based clinic for the services of an occupational therapist in fabricating splints or constructing adaptive devices for the arthritic patient. As you well know, many voluntary health insurance contracts simply do not cover ambulatory care by physicians or other health professionals. We urge you to consider the need, therefore, to provide additional funds for the centers' operational expenses, including staff.

Mr. Chairman, the American Occupational Therapy Association is grateful for this opportunity to support H.R. 14181. I would be pleased to respond to any questions.

Mr. ROGERS. Thank you. We appreciate your view.

I believe that concludes all of the testimony by the panel.

Any questions?

Mr. CARTER. I have no questions.

It was almost like a refresher course in rheumatology, for which I am thankful. I enjoyed the panel thoroughly.

I wish them well on their way on trips home and certainly we are going to do our best to see that this bill is passed and a bill of assistance to the third party.

Thank you, Mr. Chairman.

Mr. ROGERS. Thank you.

Mr. Heinz.

Mr. HEINZ. Mr. Chairman, I would like to, first of all, compliment the panel. They have given us some very useful background information. I am extremely grateful for this educational opportunity.

From the work that I have done with senior citizens, there is no doubt in my mind that arthritis, in many of its manifestations, is a tremendous problem. Surely our closest attention is required if we are ever to conquer this disease.

I do have a few questions regarding the legislation that the subcommittee will be considering and hope we will mark up very shortly.

As you know, we have two basic pieces of legislation before the subcommittee. Have you had a chance to look at both bills together?

To what extent do you feel the two bills should be merged?

There are certain choices to be made among the pieces of legislation. It strikes me in enacting both of them together would be somewhat duplicative. Do you share my——

Dr. SHULMAN. Yes. I think you are referring to the Senate bill and House bill.

Mr. HEINZ. Yes; I think that would be fair to say.

Dr. SHULMAN. One is the Senate National Arthritis Act, and your act.

My response would be that the two bills are complementary. There are some features in your bill that are lacking in the other. For the most part, your bill is more comprehensive.

The important inclusion, for example, for intramural orthopedic research program, which is extremely important, we would hope you would fight for. The support for establishing programs in medical schools that do not have any rheumatology programs at all is also vital, especially for the entire health care of the Nation.

This bill did have the advantage of the report on the workshop on arthritis centers which Dr. Donaldson and I helped to organize, and, in which the rest of use here and others participated. There was further input from the workshop.

The important thing, however, is that both bills do complement one another.

Mr. HEINZ. Thank you.

One other question. Perhaps this was touched on during the one or two moments I had to be absent this afternoon, but has there been any research on the possibility of looking into the contributions of diet on certain forms of arthritic sensitivity and any relationship between diet and autoimmunity? Other than what you might term in layman's language, are there not relatively low background—other substances you may ingest one way or another. Is this considered an area of productive research or is this just something that is not terribly productive?

Dr. SLEDGE. In two very important areas, diet is important. One is in the most common arthritis, osteoarthritis. There is a clear relationship between sheer body weight and structural joint damage.

Another rare form of arthritis, ochronosis is characterized by the faulty accumulation of certain intermediary products of digestion, leading to damage of cartilage. So there are certainly in these two areas clear example of the importance of diet.

Mr. HEINZ. Any with respect to rheumatoid arthritis?

Dr. SHULMAN. Not that I am aware of.

Mr. HEINZ. Mr. Chairman, I have no further questions at this time.

Mr. ROGERS. Might I say we have also had testimony from the American Physical Therapist Association, National Council for Schools, Retired Teachers Association, American Academy of Pediatrics, all support the legislation.

Dr. Shulman, we are grateful to you, Dr. Sledge, Miss Maynard, Dr. Hess, Dr. Howell, Dr. Donaldson, we are grateful to you for being here. Your testimony has been most helpful.

Dr. SHULMAN. We are most grateful to you for all that you have done.

Mr. ROGERS. Committee stands adjourned.

[The following statement and letters were received for the record:]

STATEMENT OF VIRGIL HANSON, M.D., COMMITTEE ON THE HANDICAPPED CHILD, THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics recognizes arthritis as a major health problem in the United States affecting both adults and children. As the seriousness of arthritic afflictions are often overlooked in the pediatric population, the following information concerning arthritis in children is submitted for consideration in planning a national program for arthritis.

NUMBER 1—DEFINITION

Arthritis in children as in adults is characterized by acute and chronic inflamation in the tissues lining the joint cavities. Symptomatically it is characterized by pain, swelling and limitation of motion and in its chronic form results in the destruction of cartilage and bone adjacent to the joints, deformities, and inability to move the affected joints.

NUMBER 2—PREVALENCE

Juvenile rheumatoid arthritis is the most common form of arthritis in childhood and affects an estimated 250,000 children in the United States. There are probably equal numbers of children who develop arthritis from other causes and a list of these is attached (Appendix A). Many of these diseases are closely related to juvenile rheumatold arthritis and crippling may result from these diseases as well as from juvenile rheumatoid arthritis. Their consideration is essential in planning an arthritis program for children but much remains to be learned concerning these related conditions in the pediatric age group.

According to Dr. Jane Schaller, the number of children affected by juvenile rheumatoid arthritis in any one year exceeds the number of children affected by all forms of malignant neoplastic disease and is larger than the total number paralyzed by poliomyelitis in a total of any ten of the pre-immunization epidemic years. Juvenile rheumatoid arthritis begins most commonly between the ages of 1 and 5 years. More than half the children will ultimately recover but many thousands will reach maturity each year severely crippled.

NUMBER 3—CLINICAL CONSIDERATIONS

The effects of Juvenile Rheumatoid Arthritis are:

(1) Crippling due to destruction of joint tissue and bone and the formation of scar-like repair tissue in 30% or more of the cases.

(2) Visual impairment occurs in 10% or more due to inflammation of the eyes which may lead to blindness.

(3) Impaired growth.

(4) Daily high fevers lasting months or years are common.

(5) Inflammation around the heart (pericarditis) occurs in one-third or more of the children.

(6) Early diagnosis and treatment are helpful in preventing disability but no cure is yet available.

NUMBER 4—DIFFERENCES FROM ADULT RHEUMATOID ARTHRITIS

Juvenile rheumatoid arthritis differs from the adult form of the disease in the frequency of high fever, greater tendency to recovery but a more rapid progression of the severe forms, growth impairment, and a higher incidence of severe eye involvement. Psychological problems, familial relationships and the need for education differ from the psycho-social problems of adult rheumatoid arthritis.

NUMBER 5—PROBLEMS

(1) There is no cure for juvenile rheumatoid arthritis and the related disorders as the cause is not known. The result is severe crippling for thousands of children each year.

(2) Medications have been approved for the treatment of adult rheumatoid arthritis but are not available for children because of the lack of facilities to carry out the needed clinical trials in children. Hence, we find ourselves extremely limited in the medications we can use for treatment. Since the physiology of the growing human organism differs from that of the mature state, adequate carefully controlled trials of new anti-arthritic drugs in children are essential.

(3) Information is lacking concerning many of the related arthritic disorders in childhood. These conditions need study and further definition.

(4) General knowledge of the diagnosis and treatment of arthritis in children is lacking among physicians and allied health personnel. Here at Children's Hospital in Los Angeles we may take a child into our rehabilitation program for a prolonged period of time. Upon returning that child to his home, community, we find that the result of our rehabilitation care has been lost, not due to the indifference of the local professional people, but due to their lack of information as to how to treat the arthritic child.

(5) There are inadequate numbers of trained pediatric rheumatologists and

supporting personnel to cope with the problem. It is estimated that there are only 30 trained pediatric rheumatologists working in 15 inadequately staffed centers in the United States, a ratio of one pediatric rheumatologist to 15,000 arthritic children.

NUMBER 6—RECOMMENDATIONS

(1) The establishment of arthritis centers for children in all major regions in the United States is recommended. Specific centers for children would be particularly advantageous for centers serving large populations, as the problems of the pediatric age group have many specialized characteristics. In less populous areas, centers capable of treating both adults and children may be the only practical means of handling the problem.

(2) The functions of the arthritis centers serving children should include: (1) comprehensive care; (2) basic clinical research related to arthritis in childhood; (3) training of physicians and allied health personnel; (4) dissemination of information to professionals concerned with the care of children in the adjacent and outlining areas of the center's region.

(3) These centers should encourage and aid the development of secondary centers or clinics in other institutions or new facilities where none exist.

(4) The ultimate goal of the program should be the establishment of at least one major center for children with arthritis in each region of five million people in the United States.

NUMBER 7—DISCUSSION

Improvement of care requires not only improvement of medical, surgical, and physical means of treatment, but improvement in knowledge where the patient lives. The center's responsibility therefore should be to provide constantly updated information in a meaningful way to the professionals in the local treatment area. The physical therapist, the occupational therapist, the educators and the child's family as well as the physicians all need to receive information provided in such a way as to emphasize what is really known and what is speculative. Such an educational effort would require the development of new educational programs but the technology is available for the rapid dissemination of information and the educational aspects of the center's function should have high priority.

It is important that research be an integral part of the program of the arthritis centers and particularly is this true in childhood arthritis. Many of the childhood syndromes of arthritis remain to be thoroughly defined and the physiology of the growing human organism gives rise to problems distinct from those seen in the mature state. Furthermore, the discipline of research provides the needed critical approach required for the development and evaluation of new modes of therapy.

There can be no doubt that arthritis is a major cause of disability in the United States but improved knowledge and treatment can substantially reduce this burden on our population.

APPENDIX A

DISEASE ASSOCIATED WITH ARTHRITIS IN CHILDREN

Juvenile Rheumatoid Arthritis
Rheumatic Fever
Lupus Erythematosus
Dermatomyositis
Scleroderma
Systemic Angitis
Polyarteritis Nodosa
Ankylosing Spondylitis
Psoriatic Arthritis
Reiter's Syndrome
Regional Enteritis
Ulcerative Colitis
Chronic Active Hepatitis
Periodic Fever
Familial Mediterranean Fever
Palindromic Rheumatism
Hemophiliac
Hypertrophic Osteoarthropathy
Fabry's Disease
Reflex Dystrophy
Toxic Synovitis
Infectious Arthritis
Psychogenic Rheumatism

SUGGESTED AMENDMENTS AND JUSTIFICATION FOR INCLUSION IN THE REPORT

H.R. 14181, "ARTHRITIS PREVENTION, TREATMENT, AND REHABILITATION ACT OF 1974"

Sec. 2(a) Finding and Declaration of Purpose—add: (6) the severity of arthritis in children and most adolescents is greater than in adults and this involves greater problems in the management of the disease.

Justification.—Children are a major and often overlooked factor in arthritis. Juvenile rheumatoid arthritis, the most common form of childhood arthritis, affects an estimated 250,000 children in the United States with an additional 250,000 who develop arthritis from other causes. As in the case of cancer and heart disease, childhood arthritis is often more severe than adult cases. Juvenile rheumatoid arthritis can stunt growth, blind, cripple, deform, disable, and even kill since it is a systemic disease. Approximately 30% of the children that develop rheumatoid arthritis will reach adult life with severe to very severe crippling. Onset of this disease is commonly between the ages of one to five years. Many of these children who goon to severe crippling are affected by an unrelenting rapidly progressive destruction of bone and joint tissue.

Sec. 3(b)(1) Six members appointed by the Secretary of HEW from scientists or physicians who are not in the employment of the federal government, who represent the various specialties and disciplines involving arthritis and related musculoskeletal diseases, and of whom at least two are practicing clinical rheumatologists, one is a practicing pediatrician, and one is an orthopedic surgeon.

Justification.—The problems of the pediatric age group afflicted with arthritis have many specialized characteristics. Juvenile rheumatoid arthritis differs from the adult form of the disease in the frequency of high fever, greater tendency to recovery but a more rapid progression of the severe forms, growth impairment, and a higher incidence of severe eye involvement. Psychological problems, familial relationships and the need for education differ significantly from the psychosocial problem of adult rheumatoid arthritis. The pediatrician, as the primary care provider to these 300,000 afflicted children, can best address their special needs.

Sec. 3(f)(1)(c) add: particular attention shall be directed towards new anti-arthritic drugs for use with children.

Justification.—Medications have been approved for the treatment of adult rheumatoid arthritis but are not available for children because of the lack of facilities to carry out the needed clinical trials in children. Since the physiology of the growing human organism differs from that of the mature state, adequate carefully controlled trials of new anti-arthritic drugs in children are essential.

Sec. 437 Insert after (c) The Director of the Institute shall, insofar as practicable, provide for an equitable geographical distribution of centers developed under this section with appropriate attention to the need for centers having the capability of conducting research, training, treatment, and rehabilitation programs especially suited to meeting the needs of children affected by arthritis.

Justification.—The establishment of arthritis centers for children in all major regions of the United States is recommended. Specific centers for children would be particularly advantageous for centers serving large populations, as the problems of the pediatric age group have many specialized characteristics. Many of the childhood syndromes of arthritis remain to be thoroughly defined as the physiology of the growing human organism is quite distinctive from the mature state. Since more children are crippled by arthritis in any given year than were crippled in a total of ten pre-immunization epidemic years of poliomyelitis, it is imperative that centers direct their attentions to the special needs of the pediatric population.

STATEMENT OF ROBERT A. TECKEMEYER, DIRECTOR OF GOVERNMENT RELATIONS, AMERICAN PHYSICAL THERAPY ASSOCIATION

Mr. Chairman and members of the Subcommittee on Health of the Committee on Interstate and Foreign Commerce, it is a privilege and a pleasure to be given the opportunity to comment on H.R. 14181, a bill to provide for the development of a long-range plan to advance the national attack on arthritis and related musculoskeletal diseases and for arthritis training and demonstration centers and for other purposes.

The American Physical Therapy Association which I represent is comprised of some 22,000 active physical therapists throughout the United States who daily attempt to meet the challenges of one of the arch cripplers of humanity, arthritis. As physical therapists, we have a firsthand knowledge of many of the extreme problems that arthritis and its related musculoskeletal diseases work upon the people of this country. Although we feel that we have been able to bring some percentage of relief to the many suffers of arthritis and while the rehabilitation programs, both large and small, are attempting to return the

sufferers of arthritis as close as possible to a normal way of life, we realize there is much to be learned about the disease process itself; that special research into this process is vital if we are to continue to progress against this massive handicapper.

Therefore, Mr. Chairman and Mr. Carter, I commend you for bringing forth a bill designed to address itself to the problem of arthritis. The program laid out in H.R. 14181 certainly approaches the subject with more than one solution. The establishment of a National Commission on Arthritis and Related Musculoskeletal Diseases is long overdue and the American Physical Therapy Association would look forward to working as close as possible with an entity of this type.

Also, the authors of this legislation are to be commended for their long-range planning. With the knowledge that the elusive answers to these diseases will be difficult to discern, the proposed research program for investigations into epidemiology, etiology, and the prevention and control of arthritis and research into the basic biological processes are extremely necessary. Developing and evaluating techniques of treatment and technological methodologies and testing this information in field studies along with the evaluation of current rehabilitation resources is to be highly commended. The collection and storing of data in relation to this problem is a necessary aspect, as well.

But, probably more important is the development of programs which provide new techniques, new curriculums for education and training, for afterall, the true beneficiary, the arthritis patient, receives aid directly from those who have been trained in this area.

The APTA and its members wish to be on record in full support of the proposed legislation offered in H.R. 14181. Again, Mr. Chairman and members of the Committee, I wish to thank you for this opportunity to lend our support to this vital and productive legislation.

STATEMENT OF DR. ROLAND W. MOSKOWITZ, IN BEHALF OF THE AMERICAN RHEUMATISM ASSOCIATION SECTION, THE ARTHRITIS FOUNDATION

Mr. Chairman and members of the House Subcommittee on Public Health and Environment: My name is Roland W. Moskowitz. I am an Associate Professor of Medicine and Head of the Arthritis In-Patient Unit at Case Western Reserve University School of Medicine, Cleveland, Ohio. I am also a member of the Board of Directors of The Arthritis Foundation and Chairman of the Foundation's Chapter Medical Coordinating Committee which attempts to assist that organization's 73 chapters in the initiation, implementation, and evaluation of their medical programs.

In my testimony today, I would like to speak on behalf of my fellow Rheumatologists who, like myself, are members of the American Rheumatism Association Section of The Arthritis Foundation, and who as a body support the provisions of Section 438 of H.R. 14181, as they relate to improved screening, early detection, prevention and control demonstration programs in arthritis.

THE NEED FOR INTENSIFIED ARTHRITIS SCREENING AND DETECTION PROGRAMS

It has been estimated on the basis of pilot screening and detection studies, as well as clinical observation, that there are approximately 12 million persons in the United States with severe symptomatic osteoarthritis, 5 million persons with rheumatoid arthritis, and 1 million gout patients. The ability to bring medical help to persons affected with these disorders is predicated on being able to better identify those persons with these diseases in an early asymptomatic state, and early symptomatic state, or with major symptoms. In addition to detecting these persons with symptomatic or asymptomatic disease, screening and detection methods are now available which allow us to detect and identify high risk persons who are believed likely to develop some of the various arthritic disorders.

Accurate clinical diagnostic criteria for all the major rheumatologic disorders have been devised by The American Rheumatism Association and the International League Against Rheumatic Diseases. Application of these criteria and clinical screening can identify patients with possible, probable and definite rheumatic disorders.

In addition to these clinical techniques, specific diagnostic studies which can be utilized for screening large numbers of persons at reasonable costs in terms of material and time are also available. These are outlined in Part C of this testimony.

A. Screening phases

Screening for rheumatic diseases can be divided into two major phases: (1) detection of persons at high risk for development of the disease, but who do not yet have the disease; and (2) early detection and diagnosis of patients who have symptomatic disease.

Detection and therapeutic intervention in Phase 1 is preferable when possible. There are basically two aims in screening for chronic illness: Research and case finding. The primary intent of research may be to determine the prevalence or incidence of the disease, to determine the natural history of the disease, to establish the magnitude of the medical problem caused by the disease in terms of disability, morbidity, mortality and cost, and to study the role of possible causal factors in the disease. The aim of case finding is to detect unrecognized cases of the disease or to predict those who are high risk for development of the disease. Case finding is justified if the disease represents an important health problem, as in the case with arthritis, if efficient screening tests exist, if the natural history of the disease is well known, if effective treatment is available, and if intervention with treatment at an early stage results in health and economic benefits. There must also be sufficient personnel and facilities to provide follow-up therapy in newly diagnosed cases, and the cost/benefit ratio must be capable of being improved in comparison with alternative methods of medical care.

New scientific discoveries now make possible the development and testing of effective screening programs to identify not only those persons with early arthritis, but also those with a susceptibility to the development of arthritis. Detection of these persons will then allow early intervention with therapy, and alleviation of damage done by these diseases. Identification of the high risk individuals will result in more patients entering treatment programs at the earliest possible stage of the disease which can curb the progressive nature of arthritis, thereby taking advantage of improvements in disease therapy.

B. Benefits to be derived from screening and detection programs

Intensified application of presently available methods for early screening and disease detection will provide multiple specific benefits.

(1) Epidemiologic information will provide critically needed data on the natural history of these diseases and will enable the medical community to evaluate the results of various treatment programs.

(2) Epidemiologic data will also provide a groundwork of research information for our continuing effort to improve the classification of these diseases and will aid direction of research efforts.

(3) Early institution of treatment programs following identification of patients with these diseases will allow a much expanded program of prevention and reversal of the rheumatic disease processes.

(4) Identification of persons susceptible to these diseases, as well as persons already having these diseases, will allow for effective counseling in respect to job and educational goals.

C. Arthritics for which screening and detection programs are especially applicable

(1) Gout is a common form of arthritis in which epidemiological investigations and case finding would be valuable. This disease affects approximately a million people in this Country and is responsible for as many as 4.5/1000 doctor's office visits. It is a particularly debilitating illness, characterized by severe pain, kidney damage and other serious complications in a large percentage of patients. In contrast to other forms of arthritis, a highly effective treatment using combined drug therapy has become available within the past decade. If patients are maintained on these drugs under careful surveillance by knowledge physicians, the permanent sequelae of the disease including kidney disease can be averted in most cases.

Large scale epidemiologic studies have greatly increased our knowledge of the natural history of gouty arthritis. They have confirmed that individuals with hyperuricemia (high uric acid in the blood) have a manyfold greater chance of developing arthritis than normouricemic individuals. Detection and drug therapy for hyperuricemia in these individuals during the presymptomatic stage

could conceivably prevent all cases of gouty arthritis if applied on a sufficiently large scale. The relatively poor specificity of the test, however, probably dictates screening on a smaller scale, possibly to males in the 20–40 year age range, with special emphasis given to the screening of families of known cases. Applications of tests for hyperuricemia in children have been effective in detecting enzyme deficiencies which are inherited and who find to develop severe manifestations of gout, neurolgic disorders, and marked tendencies for self-mutilation.

In addition to the identification of patients with asymptomatic or symptomatic gout, serum uric acid determinations using stress testing with high purine intake will identify those patients likely to develop gout when exposed to dietary change. It has been demonstrated in several studies that various population groups have aormal uric acid metabolism when exposed to a low purine diet. Upon exposure to higher puriae diets with intake of increased amounts of meat, fish, and other high purine foods, the gonty diathesis becomes manifest. In addition to renal disease and recurrent attacks of acute arthritis which might lead to chronic deforming arthritis, hyperuricemia may well be associated with an increased propensity to the development of atheroscierosis. This propensity may be related to a common inherited platelet aggregation associated with the hyperuricemic state.

(2) Rheumatoid arthritis afflicts approximately 5 million people. It is responsible for about half of the disability and morbidity caused by all forms of arthritis. It has been estimated to account for 6.5 per cent of all physician office visits. Certainly the disease represents one of the most important health problems of this Couatry. Currently there is no test which enables us to screen individuals at high risk or during the presymptomatic stage. Therefore both intervals are completely uncharacterized. Nonetheless, case-finding screening for early manifest disease can result in substantial benefits since clinical experience demonstrates that optimal care rendered at this stage can prevent much of the disability and deformity resulting from the disease. Serum studies for rheumatoid factor utilizing the latex fixation test, which are positive in about 75 per cent of cases aad antinuclear factor in serum will identify persons with the presence of rheumatoid arthritis, or with a susceptibility to the disease.

Because of the technical difficulties of performing this test, central reference laboratories must be developed for standarizatioa of testing and evaluation procedures. Such reference laboratories are vitally important if we are to gain n fuller understanding of the onset and course of the disease. Preferably these laboratories should be established on a national basis and linked to an automated patieat data center.

(3) Systemic lupus erythematosus: Diagnostic serum studies including antinuclear factors, rheumatoid factor, or false positive serologic test for syphilis can be used to identify patients with a susceptibility to or the presence of system lupus erythematosus. Certain of these factors, such as anti-DNA are quite specific for this disorder. Additional breakthroughs ia diagnostic screening methods such as antibody to extractable-nuclear antigen (ENA) now make it possible to sub-categorize patients with mixed connective tissue disease which clinically presents as a combination of systemic lupus erythematosus, polymyositis and scleroderma. Use of these screening methods allows a more accurate classification of disease, more accurate indications of prognosis, and improved guides to therapy.

(4) Degeaerative joint disease (osteroarthritis): Screening for osteroarthritis is the most difficult of the major arthritides. Pathologic study often fails to distinguish between degenerative joint disease and simple aging of articular cartilage, a highly specialized connective tissue. However, certain symptoms and complaints are especially common and identifiable: Joint pain; stiffness following periods of rest; arching of joints during inclement weather; spasm or atrophy of surrounding muscles; limitation of motion; malalignment; and changes in the shape of joints. Inflammation is fairly uncommon. X-rays and palpation of affected joints are the most commonly used forms of detection.

The National Health Examination Survey of 1971–1972 used X-rays of 5,000 persons in an attempt to better ascertain the prevalence of this disease. Principally these X-rays of the pelvis and knees was to discover lesions, osteoporosis, cartilage destruction, bone destruction, bone growths aad cartilage growth. These X-rays are now being interpreted.

(5) Ankylosing spondylitis: An exciting new discovery relates to the identification of susceptibility to the development of various connective tissue disorders in patients with histocompatibility antigen HLA–27 (W27). It has recently been

noted that up to 90 percent of patients with ankylosing spondylitis, Reiter's syndrome, juvenile arthritis, and ulcerative colitis will have this antigen present in their HLA typing studies. Since these antigens in certain animals are linked to immune-response genes, the highly important association of these diseases with this antigen suggests that the pathogenesis of these diseases may be directly related to some aberrant, genetically controlled, cellular immune response. The availability of this diagnostic technique now makes possible its application in epidemiologic studies, disease classification, and early treatment and diagnosis of patients with these disorders.

Of interest with respect to patients identified as having W27 histocompatibility antigen is the fact that approximately 8 percent of the white population and 4 percent of the black population in the United States are positive for W27 antigen. The actual incidence of ankylosing spondylitis, psoriatic spondylitis, and colitic spondylitis is significantly smaller than the population at risk. The factors involved in the actual development of disease of arthritic nature in only some of these patients is yet to be determined. Screening studies should allow further investigative research studies directed toward eliciting what factors are involved in the development of spondylitis in these patients. It is apparent that if we know enough about a disease to predict a high risk individual, we also possess important clues as to the possible causes of these diseases. History has proven repeatedly that the development of a test to detect the high risk individual is often followed by the development of a preventive immunization or curative treatment for the disease in question.

D. Screening and detection as evaluative devices

The availability of accurate screening and detection methods and their intensified application cannot only provide critically needed information on the natural history of these diseases, but will enable the medical community to more effectively evaluate the results of various treatment regimens. Early therapy can be instituted to alleviate damage, otherwise to be anticipated by lack of early disease control.

For example, patients with early rheumatoid arthritis can be instructed in medical and physical therapy programs to prevent and reduce disease deformity. Patients with systemic lupus erythematosus can be guided as to the avoidance of precipitating disease factors such as excess sun exposure, use of allergenic drugs, and hazard and stress situations such a pregnancy which may lead to irreversible renal damage. Patients with degenerative joint disease can be instructed in preventive programs such as weight reduction and removal of strain factors which lead to more rapid progression of osteoarthritis changes. Patients with gout can be effectively treated with available medications to avoid the effects of elevated serum uric acid in induction of kidney stones and renal disease. It has been shown that up to 60 percent of patients with uncontrolled hyperuricemia will go on to develop acute attacks of gouty arthritis, possible irreversible joint deformity, and renal disease if inadequately treated. Identification of HLA antigen type will allow earlier institution of therapy based on better disease classification and a more valid application of therapeutic principles.

As noted above, accurate, effective and practical techniques for screening and detection are already available, based on research discoveries. The gains to be achieved by proper application of these techniques in terms of clinical aid, guides to research and early institution of therapeutic programs cannot be stressed too strongly.

THE NEED FOR EXPANDED ARTHRITIS CONTROL PROGRAMS

A. Drug therapy: Treatment of rheumatoid arthritis is basically unsatisfactory. At present, we have one drug which is effective in the most mild forms of rheumatic disease—aspirin. For those who can not be managed on aspirin, two toxic, non-steroidal, anti-inflammatory agents—Indomethacin and Phenylbutazone are available. Therapy with gold while effective is unsatisfactory in most cases and severe adverse effects occur. For the vast majority of arthritics who can not be handled or can not be maintained on these drugs, the only solution is either corticosteroids or immunisuppressives; both treatments result in horrendous side effects (such a overwhelming infections, diabetes, and even the induction of malignancies). Thus, the drugs presently available for the treatmeat of rheumatoid arthritis do not give satisfactory relief to the vast majority of patients. In the past two years, stimulated by the discovery of the anti-inflammatory effect of Indomethacin and because of its relatively high incidence of

severe side effects, an intensive search has been made for new non-steroidal, anti-inflammatory compounds, and about 70 of such drugs have been developed.

A major thrust of The Arthritis Foundation in the next five years will be finding which of these is best for the vast majority of rheumatoids who have mild to moderately severe disease. (We are already aware that about 5 to 10% of severe rheumatoids will be doomed to steroids and immunosuppressive therapy, and cannot be controlled on the less toxic non-steroidal agents.) If some of the new non-steroidals turn out to be less toxic and more potent than Indomethacin and Phenyl-butazone, vast benefit will accure to sufferers of rheumatic disease, and also to those with minor musculoskeletal strains. These conditions which result in the loss of thousands of days of work each year (about 5% of all days lost) and effective drugs will result in a major reduction in time loss.

The clinical testing of these compounds is difficult because of the high degree of variability of rheumatoid arthritis, and because of the sophistication in statistical design and measurement of disease activity that is required to determine if these compounds actually work. This will require the support of as many as two-hundred to three-hundred small drug trials coordinated by the Arthritis Foundation. Unless major support is available to develop and coordinate this work, an immense opportunity to relieve the pain and suffering being experienced by millions of Americans will be lost.

A history of The Cooperative Clinics Committee of The Arthritis Foundation which has undertaken seven major drug trials since 1959 and a description of some of the major new nonsteroidal anti-inflammatory agents which the CCC would test if funds were available are attached to this statement.[1]

B. Corrective surgery: Perhaps the greatest advance in recent years in the treatment of the severely disabled arthritic has been the replacement of the total hip joint with a prosthesis devised by Dr. John Charnley of England and modified by Dr. Mueller of Switzerland. Its phenomenal success in England, Europe and the United States is largely attributable to an inert non-allergenic cement substance which securely fastens the metal-plastic prosthesis in place, providing for quick recovery (1–2 weeks), reduced hospitalization and home care, less effect on adjoining muscles, and little required therapy.

Also used extensively, but of lesser efficacy is the synovectomy operation- removal of the synovium from from joint areas. When the bone or joint in the affected fingers and knees has been destroyed, then joint replacement is considered. Several such prostheses have been devised for areas other than the hip. This area is the subject of continuing investigation in order to improve upon present results.

C. Physical therapy, occupational therapy, and the use of supportive orthotic appliances: There are many forms of physical therapy, occupational therapy and orthotic devices used to treat the arthritic patient ranging from simple exercises to splinting, bracing, corrective shoes and other external posthetics. Further studies would be advantageous through the mechanism of arthritis centers in terms of evaluating the efficacy of these various forms of treatment in patient populations of adequate size and where control conditions are satisfactory to the successful measurement of the therapeutic modality being used.

The assessment of the functional condition of the arthritis patient has been greatly aided by the development of four classifications of patients ranging from little or no handicap to near or complete incapacitation. This analysis is of significant help in the advocacy of individualized therapeutic regimens.

RE-EMPLOYMENT OF THE DISABLED ARTHRITIC

A. Dimensions of the problem. Social Security records show that arthritis—American's #1 crippling disease—is second only to heart disease as a cause of disability.

Arthritis accounts for 15 percent of all disability payments. The problem of the arthritic patient as it relates to industry involves several components. One is the relationship of occupation to the etiology of certain rheumatic problems. Evidence indicates that some forms of rheumatic disease, particularly degenerative joint disease of peripheral joints of the spine, are in part occupational and thus preventable or capable of modification so that they no longer impinge on the more active phases of working life. In addition, it is important to evaluate the prevalance of rheumatic complaints in the working population and to assess

[1] Not printed.

the effect on working capacity and work lost. Finally, and of major import both to the individual patient and to industry, is the problem of employability of the arthritis patient. The costs of unemployability due to arthritis are staggering, in direct expenditures, unearned income, unpaid taxes, and unrealized potential, in addition to the direct medical discomfort and disability these diseases pose to to the individual patient.

B. How effective is rehabilitation of the arthritis patient? It has been demonstrated in a number of studies that patients with major arthritic diseases are capable of effecive full time or part time employment. In one such study, carried out by Drs. H. Robinson and K. Walters, of Vancouver, British Columbia, for the Canadian Arthritis and Rheumatism Society, it was demonstrated that over 50 percent of patients with severe rheumatoid disease could be employed full time or part time when effective comprehensive rehabilitation programs were carried out. This employability represented a significant savings in public funds in addition to other benefits provided to these patients.

The goal is to place the handicapped arthritic individual in profitable employment, so that he retains his dignity, avoids becoming a public charge, and resumes his place as a tax paying citizen beholden to no one. Such a person selectively placed and adequately followed affords an unusual opportunity to reach this goal with safety to his fellow workers, enhanced stature to himself and his family, and with financial reward to the employer.

A review by the New York State Employment Service demonstrated that at least one out of every four arthritics applying for help was able to be placed. Of specific interest was the fact that 80 percent of the patients who were placed were in the age group 45 years or older.

By use of intensive rehabilitation programs, approximately 60 percent of patients with rheumatoid arthritis followed by the Columbia Presbyterian Medical Center were shown capable of maintaining employment in various job positions including industrial jobs, clerical work, service jobs and a variety of other occupations. Goals of therapy and rehabilitation should include those directed towards decreased absenteeism, employment for the first time of those patients with arthritis, and return of arthritic patients to their previous place of employment. Great ingenuity has led to the availability of adaptive equipment and work methods for the severely handicapped which allow successful employment in industry. Self-help devices reduce energy costs. Transit to and from work can be designed to provide soluble practical methods for maintaining employment. It is obvious that reduced absenteeism and continued employability of patients with arthritis diseases can lead to substantial savings in terms of monies otherwise to be provided by public welfare programs.

C. What is needed? Effective placement requires taking advantage of good personal attitudes and motivation on the part of the patient, rehabilitation techniques, intensive medical therapy and full cooperation with knowledgeable persons in industry. Emphasis needs to be placed on changing employers' attitudes from negative to positive in accepting handicapped workers.

Rehabilitation with respect to employment requires a team effort program. The team includes the individual patient, his employer, social services already available in the community and others to be added, physical therapy and occupational therapy facilities, vocational guidance and placement services, workshops, and knowledgeable people in industry. Rehabilitation efforts should be started as soon as practical after the patient's evaluation. A review by vocational counselors allows determination of prognosis of disease and the presence of disability which might adversely affect future employment. It is essential that the counselor have intimate knowedge of the requirements of the job in which the patient is to be employed and to provide confidence to the patient in his future. It is essential as well that the counselor have detailed knowledge of the place of employment and to visit the employer directly. Close contact both with union and management personnel is of major importance. Employers should be encouraged to keep jobs open for the patients and to allow modifications or alterations to the job if feasible to allow continued employability.

Although some of the goals identified above can be accomplished to some degree by presently available resources, maximal achievement in solving the problem of employment of arthritics in industry requires development of large, well-organized work classification and employment centers. Scientific analysis of the results of the application of presently available techniques as well as development of innovative methods can be of great benefit in allowing introduction of

these resources to be used by smaller centers and by already functioning community resource persons interested in this problem. It is unfortunate that while great strides have been made in research efforts directed toward many aspects of the rheumatic diseases, socioeconomic studies and programs have lagged seriously behind. This lag is due not to lack of intent by interested persons, but rather, due to lack of sufficient finances and resources to develop the knowledge and the numbers of interested and capable personnel required to affect desired goals. The cost-benefit ratios to be achieved by successful expanded introduction of methods directed toward rehabilitation of the arthritic patient are enormous when compared to programs in which such efforts are not being carried out.

STATEMENT OF CYRIL F. BRICKFIELD, LEGISLATIVE COUNSEL, THE NATIONAL RETIRED TEACHERS ASSOCIATION AND THE AMERICAN ASSOCIATION OF RETIRED PERSONS

I am Cyril F. Brickfield, Legislative Counsel to the National Retired Teachers Association and the American Association of Retired Persons, affiliated, nonprofit organizations having a combined membership of over seven million older Americans. Our Associations appreciate this opportunity to express our strong support for HR 14181, the Arthritis Prevention, Treatment and Rehabilitation Act of 1974.

The impact of chronic arthritis on older Americans is striking: 85 percent of those 65 and older living outside institutions have experienced irreversible impairment that leaves a residual disability. While a number of these individuals experience no physical limitation of their activities, there is a direct relationship between physical impairment and age. Given the facts that the oldest segment of our population is expanding the fastest and the rate of impairment to this age group is directly related to age—over 50 percent of those older Americans 75 and older have a chronic condition which limits their activities—the crusade against arthritis has a major impact on the health of our elderly.

Although it is impossible to measure the amount of human pain, suffering and anguish present in older persons lives as a result of our nation's number one crippler—arthritis, it is significant to note that over 80 percent of persons 65 and older are afflicted with the disease. The astonishing prevalence of arthritis in the United States has long mandated research activities which would facilitate better methods of treatment and prevention, as well as better methods of rehabilitating those permanently afflicted with the disease. We believe HR 14181 would effectively tap the enormous potential of our nation's health resources and give arthritis research the attention and high priority it deserves.

Concerned with the proportions of this disease and its effect on our members, the National Retired Teachers Association and the American Association of Retired Persons have recently undertaken a national program of Arthritis Education. Through this program we have endeavored to bring accurate information about cures and treatments of arthritis to older persons. The timeliness and importance of this new program was underscored by the fact that during its first six months of operation, bookings were requested for presentations in nearly 200 communities throughout the United States.

The education program was developed and coordinated with the Arthritis Foundation. It organizes discussion sessions in local communities which are led by a recognized authority on arthritis. The ensuing dialogue which occurs between the resource persons and the elderly at these sessions has provided a dramatic illustration of the high degree of misperception and misinformation shared by older persons. Many individuals still maintain erroneous beliefs in the value of a variety of cure-alls for arthritis. In an effort at self-treatment of their disease, they often use substances of a potentially injurious nature. More importantly they run the additional risk of exacerbating their condition by their delay in seeking proper medical attention. Our experience thusfar has illuminated the need for more educational programs of this type.

While education programs designed to remedy problems of misinformation are important, it is still a primary concern of our Associations to encourage scientific research for the cure and prevention of arthritis. Until either a cure is found or more successful treatment methods are developed, it is likely that older individuals will further endanger their health and arthritic conditions by resorting to self-administered health care. Older Americans are most susceptible to this risk

because they, more than any other age group, are adversely affected by the high cost of health care. Not being able to afford proper medical advice, they resort to their own sometimes dangerous treatment. For this reason, it is essential that programs of research and medical treatment be continued as part of an overall approach to deal effectively with a disease that afflicts a major portion of the elderly population.

The National Retired Teachers Association and the American Association of Retired Persons believe that HR 14181 would facilitate a research program to deal with this major national health problem by coordinating its program with the National Institutes of Health and thereby improving the allocation and utilization of scarce medical resources. A well-funded research program would not only reflect the seriousness and prevalance of arthritis, but would ensure more adequate and consistent funding levels—an assurance arthritis research has not had in the past. Previous insufficient funding has resulted in a lack of medical personnel trained specifically in rheumatology. There are not enough qualified physicians to take care of the millions afflicted. The neglected victims of arthritis should no longer suffer from this regressive health care delivery system. With increased funds, researchers could be actively encouraged and trained to work in this field.

The proposed funding by HR 14181 of a number of National Arthritis Training and Demonstration Centers would coordinate various efforts being made in the arthritis field by serving as regional foci for intensive research and headquarters for training in diagnostic and preventative methods. These Centers would also aid the development of training and education opportunities for physicians and allied health personnel. Screening, detection, prevention, and control programs would be developed and, aided by the standardization of arthritis patient data, will improve the quality and delivery of arthritic patient care. HR 14181 also provides assistance to medical schools which have no arthritis teaching program, enabling each of these schools to acquire a rheumatologist as a member of its faculty. A 17-member Commission on Arthritis and Musculoskeietal Diseases would be established to survey and assess the adequacy and coordination of arthritis programs and to formulate a long-range plan to combat arthritis. In view of these comprehensive and forward-looking provisions our Associations urge the passage of HR 14181.

Enactment of the Arthritis Prevention, Treatment and Rehabilitation Act of 1974 would signify a long overdue national commitment to arthritis victims. Arthritis has cost millions of Americans many hours of pain and suffering. The retirement years for many of our older Americans which should be rewarding and fulfilling have been filled with anxiety from discomfort and disability due to arthritis. Thus, let us delay no longer in offering our arthritis victims some hope and relief. The National Retired Teachers Association and the American Association of Retired Persons believe the time has come to make a concerted effort to end this disabling disease and therefore urge the adoption of HR 14181.

Statement of Maharishi International University

Mr. Chairman: Maharishi International University of Fairfield, Iowa, has been monitoring scientific research on the practice of Transcendental Meditation (TM), including that exploring TM's usefulness in clinical and preventative medicine. In light of the aims of the Task Force on Arthritis to develop an "Arthritis Plan," we would like to bring to the attention of the Subcommittee some of these finding which we feel are relevant and merit further investigation.

I. SCIENTIFIC RESEARCH

In June, 1971, Stephan E. Mergenhagen, Ph.D., and Ralph Snyderman, M.D., of the National Institutes of Health wrote in *The Journal of Infectious Diseases:* "Among the diseases that affect mankind, the pathogenesis of a group of inflammatory diseases of uncertain etiology is receiving increasing attention because of their high prevalance in the population as well as their high morbidity and occasional mortality. This group includes such diseases as rheumatoid arthritis, acute and chronic glomerulonephritis, lupus erythematosus, periarteritis nodosa and sarcoidosis. . . .

"In this editorial, we wish to call attention to periodontitis, another inflammatory disease of incompletely established etiology affecting the majority of the

adult population. Though tissue damage due to the host's reaction plays a major role in this disease, it has received little attention from students of infectious and inflammatory disease. . . .

". . . The fact that periodontal tissues are far more accessible for study than joints, kidneys, or the heart, should lead more investigators to study the pathogenesis of periodontal disease as a model of infectious and inflammatory disease."[1]

Practitioners of Transcendental Meditation (TM) and controls were examined clinically for degree of oral inflammation repeatedly. Improvement was seen in 74% of the meditators versus 15% of the control group ($N=72$, $P<.001$ using X^2 test), suggesting that TM strengthens the immune system and regenerative capacity, providing a stronger basis for health.[2] Inflammation of the gingiva (margins of the gums) results from local and systemic stress factors. Gingivitis precedes the degeneration of underlying bone (peridontal disease) which occurs in a vast majority of the population and ultimately results in loss of teeth and nutritional imbalance.

Other findings on the effectiveness of TM in easing and eliminating stress-related physiological disorders include:

In a retrospective study of meditators who previously suffered from allergies, over half reported a decrease or cessation of allergies ($N=156$).[3]

After beginning the practice of TM, 94% of a group of asthmatic patients showed improvement as determined by the physiological measurement of airway resistance. Sixty-one percent of the asthmatic patients showed improvement as reported by their personal physicians and independently by the patients themselves.[4,5]

Arthritis refers to any inflammatory involvement of a joint. Hypersensitivity has been named as a probable cause of arthritis and recurrent attacks of arthritis are sometimes triggered by emotional stress. Similarly, bronchial asthma and periodontal disease are typically characterized by inflammation due to hypersensitivity and often emotional distress. Thus, the research evaluating TM's beneficial effect upon allergies, bronchial asthmas and periodontal disease may be of significance to arthritis research.

The reduction in high blood pressure; reduced use of alcohol, cigarettes and other drugs; normalization of weight; improved emotional stability as measured physiologically and psychologically; and relief from insomnia, all observed associated with the practice of TM, suggest that the technique is effective in counteracting undesirable behavior and tendencies resulting from stress. These studies have been previously reported to this Subcommittee.[6]

With 50 research projects completed-to-date and approximately 200 studies in progress at major universities and institutes in over 40 countries, the International Center for Scientific Research of Maharishi International University serves scientists and students as an information clearinghouse. Further information on scientific research evaluating TM can be obtained from ICSR, 1015 Gayley Avenue, Los Angeles, California 90024.

II. CONCLUSION

Sufficient similarities exist in the signs, possible etiologies and therapies to warant further investigation into the value of Transcendental Meditation in altering arthritis and other inflammatory diseases. Therefore, we urge the Task Force on Arthritis to make full use of MIU's research capabilities and draw

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[1] Mergenhagen, Stenhan E. and Ralph Snyderman, "Periodical Disease: A Model for the Study of Inflammation." The Journal of Infectious Diseases, Vol. 123, No. 6, June 1971, University of Chicago, Illinois.

[2] Klemons, I. M., "Changes in Inflammation Which Occur in Persons Practicing Transcendental Mediation," College of Health, Physical Education and Recreation, Pennsylvania State Univ., University Park, Pa., 1972. Unpublished manuscript.

[3] Panentin, F. "Self-Purification of the Organism and Transcendental Mediation: A Pilot Study," Scientific Research on Transcendental Meditation: Collected Papers, Orme-Johnson, D. W., L. Domash and J. Farrow (Eds.), Vol. 1, Los Angeles, MIU Press, 1974.

[4] Honsberger, R. and A. F. Wilson, "The Effects of Transcendental Meditation Upon Bronchial Asthma," Clinical Research, Vol. 2, No. 2, 1973, USA.

[5] Honsberger, R. and A. F. Wilson, "Transcendental Meditation in Treating Asthma," Respiratory Therapy: The Journal of Inhalation Technology, Vol. 3, No. 6, pp. 79–81, November-December 1973, USA.

[6] Subcommittee on Public Health and Environment of the Committee on Interstate and Foreign Comerce, House of Representatives, Ninety-Third Congress: Hearings on a National Health Policy and Health Resources Development, March 15; April 30; May 1, 6, 7, 8, 9 and 14, 1974: Statement of Ian MacPherson Brown,

on any or all of the University's 400 external learning centers and 6,000 trained teachers of TM in the U.S. when drafting and implementing the "Arthritis Plan".

MARY J. BELCHER,
Special Assistant to the Vice President.
IAN MACPHERSON BROWN,
Co-Director of Resource Development.
GEORGE L. HELLAND,
Co-Director of Resource Development.

UNIVERSITY OF MIAMI,
Coral Gables, Fla., November 21, 1974.

Representative PAUL ROGERS,
House of Representatives,
Washington, D.C.

DEAR REPRESENTATIVE ROGERS: I most wholeheartedly recommend that the National Arthritis Act which is now being considered by the House, be passed.

Having always been involved with physical conditioning and injuries may I add my support to the importance of this bill which affects so many people that it has to be very vital.

Thank you for your consideration.

Sincerely,

PETE ELLIOTT,
Head Football Coach and Athletic Director.

BAYLOR COLLEGE OF MEDICINE,
DEPARTMENT OF INTERNAL MEDICINE,
Houston, Tex., November 21, 1974.

Hon. BOB CASEY,
Member, House of Representatives,
U.S. Congress

DEAR MR. CASEY: My reasons for support of the Arthritis Act (House Bill—H.R. 14181) are as follows:

The various forms of arthritis are among the nation's most common causes of physical disability, loss of earning power, and human suffering in our nation today;

Although most cases of arthritis can be cared for quite well by family practitioners and general internists, with recent advances in medical knowledge many patients suffering from arthritis will benefit greatly from specialty consultation or care;

The number of trained rheumatologists is woefully inadequate to meet this need and the distribution of those specialists available has left many areas of the nation with little or no specialty care available. For example, in Texas, whose population now includes two million people who already have arthritis or will develop this condition during their lifetime, there are fewer than twenty rheumatologists and most of these are located in four urban centers.

The National Arthritis Act, by establishing centers that will provide specialty training and continuing education, basic and clinical research, and screening, detection, and treatment programs represents a major step forward in the provision of effective medical care for the nation's many patients suffering from arthritic diseases.

Your support in urging the members of the Subcommittee on Public Health and Environment to send this bill to the floor of the House for action in this session is greatly appreciated.

Sincerely,

JOHN T. SHARP, M.D.,
Professor of Medicine,
Chief, Section of Rheumatic Diseases.

CHILDRENS HOSPITAL OF LOS ANGELES,
Los Angeles, Calif., November 22, 1974.

HON. PAUL G. ROGERS,
Chairman, Public Health and Environment Subcommittee,
Rayburn Office Building, Washington, D.C.

DEAR CONGRESSMAN ROGERS: I want to thank you for your interest in arthritis and to express my full support for the "Arthritis Prevention, Treatment, and Rehabilitation Act of 1974," H.R. 14926 which you have introduced. Here at the Childrens Hospital of Los Angeles we have had for many years one of the worlds largest clinics for arthritic children and on the basis of this extensive experience can fully endorse the comprehensive program which you have outlined in H.R. 14926.

With the approval of Dr. Edmund Ackell, Vice President for Health Affairs of the University of Southern California, I should like to express to you my concern that specific provision should be made for arthritis centers for children in any national arthritis program.

The problems we see are as follows:

1. We need to know more about the different kinds of arthritis as they affect children, which means increased research.

2. We need to improve the treatment of arthritic children, both here and in outlying areas.

3. We need to disseminate the information which we already have and that which will be developed, to wide areas and particularly to the professionals of all disciplines involved in child care.

4. Medications have been approved for the treatment of adult rheumatoid arthritis but are not available for children because of the lack of facilities to carry out the needed clinical trials in children. Since the physiology of the growing human organism differs from that of the mature state, adequate carefully controlled trials of new anti-arthritic drugs in children are essential.

I could not, I believe, over emphasize these four points. The internist rheumatologists do not feel that enough is known about arthritis in adults and certainly general knowledge and facilities for treatment for adult arthritics are woefully inadequate. Even less is known about childhood arthritis and treatment facilities except for a few scattered facilities in the United States are completely undeveloped. There are approximately one-half million children afflicted with some form of arthritis in this country and whenever a new center is established it is immediately utilized and more. This phenomenon we observed again recently in Hawaii when one of our former trainees established a clinic for children with arthritis there.

The program that is needed is to establish arthritis centers for children which would provide comprehensive care, conduct both basic and clinical research, and to disseminate information and training to help professionals in the adjacent and outlying areas of the major centers region. The child arthritic is often facing a young lifetime of treatment and, in fact, most of his treatment will be given at or near home and not within the arthritis center itself. Coordination of the child's care with his education is another important facet of his continued treatment in his home community. A specific responsibility of major centers, therefore, should be to encourage and aid the development of secondary centers or clinics in other institutions or new facilities where none exist.

It is important that research be an integral part of the program of the arthritis centers and particularly is this true in childhood arthritis. Many of the childhood syndromes of arthritis remain to be thoroughly defined and the physiology of the growing human organism gives rise to problems distinct from those seen in the mature state. Furthermore, the discipline of research provides the needed critical approach required for the development and evaluation of new modes of therapy.

Improvement of care requires not only improvement of medical, surgical, and physical means of treatment, but improvement in knowledge where the patient lives. The center's responsibility, therefore, should be to provide constantly updated information in a meaningful way to the professionals in the local treatment area. The physical therapist, the occupational therapist, the educators and the

child's family, as well as the physicians all need to receive information provided in such ways as to emphasize what is thoroughly known and what is speculative. Such an education effort would require the development of new educational programs but the technology is available for the rapid dissemination of information and the educational aspects of the center's function should have high priority.

In any legislation for arthritis I think it is particularly important that specific provisions be included for child arthritis centers for the reasons fairly well delineated above. The problems of childhood arthritis are different due to the growing nature and immaturity of the child, the problems of childhood arthritis are less well understood and defined than in adults, and arthritis is one of the significant causes of crippling in childhood. I would recommend that there should be one major arthritis center for children for each population area of five million people, or approximately 40 such centers throughout the United States. The annual budget required for the operation of one such center would be approximately $250,000. There are not enough trained personnel to man such centers at the present time, but there are resources for such a program to begin with 15 centers at the present with a growth to 30 within five or six years.

I am enclosing a copy of the statement of the American Academy of Pediatrics on arthritis in children.[1]

Sincerely yours,

VIROIL HANSON, M.D.
Professor of Pediatrics.

UNIVERSITY OF WASHINGTON,
SCHOOL OF MEDICINE,
DEPARTMENT OF PEDIATRICS,
Seattle, Wash., November 26, 1974.

Hon. PAUL ROGERS,
Rayburn House Office Building,
Washington, D.C.

DEAR REPRESENTATIVE ROGERS: Juvenile rheumatoid arthritis is one of the most common and potentially disabling diseases of children in our country today. There are currently in the United States some 250,000 children suffering from rheumatoid arthritis, more children than those who have leukemia and other malignancies, more children than those who have diabetes, more children than those who were paralyzed with poliomyelitis during ten epidemic years, and yet many people do not even know that this disease exists, many physicians fail to recognize and treat it properly, and in this country with its generally high standards of medical care there are only about 30 specialists particularly trained to treat these quarter of a million affected children and only ten or so centers which might be said to specialize in their care. Very little is known about basic causes of rheumatic diseases in children which must be understood before any truly effective therapy or means of prevention of these diseases will be found. This is indeed a sorry state of affairs and one which I would like to bring officially to your attention. There is obviously a great need for increased emphasis on rheumatic diseases in children, and for means to train more specialists in this field and to do the needed research into basic disease mechanisms and new forms of therapy.

I am a pediatrician, an associate professor at the University of Washington School of Medicine and the Director of the Childrens Arthritis Clinics at the University and Childrens Hospitals. We have in Seattle a major center for the diagnosis and care of children with rheumatoid arthritis and other rheumatic diseases. We see children from a 10-state area and manage over 1200 patient visits a year. The outlook for our patients and all children like them could be vastly improved by an increased accessibility to funds supporting research and training of specialists.

Now pending before the House is H.R. 14181, the "Arthritis Prevention, Treatment, and Rehabilitation Act of 1974". I and my patients would be delighted if you would be willing to cosponsor this bill, and we urge you to support it wholeheartedly.

I would also suggest the following specific additions to the bill to allow special attention for our many children with rheumatic diseases:

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[1] See p. 203 for statement referred to.

1. In Section III concerning the composition of the National Commission on Arthritis and Related Musculoskeletal Diseases: The membership should include a pediatrician.

2. An amendment to the bill should be inserted making allowances for children with rheumatic diseases. An appropriate amendment was added to the Senate Arthritis Bill [S2854, Section 439B(d)] which asks that "appropriate attention be given to the need for arthritis centers having the capability of conducting research, training, treatment and rehabilitation programs especially suited to meeting the needs of *children* affected by arthritis". We need to establish arthritis centers for children which would provide comprehensive care, conduct both basic and clinical research, train specialists to treat children with rheumatic diseases, and disseminate information and training to help professionals in outlying areas. It would seem reasonable that one major arthritis center for children should exist in a population area of about five million people; this would mean about 40 such centers throughout the United States. The annual budget required for the operation of one such center would be about $250,000.

I and my patients are grateful to you for any interest you express in arthritis. I would be delighted to have you visit my Clinics anytime and meet my patients firsthand. Enclosed is a copy of testimony I gave before the Senate Appropriations Committee this summer which provides some more information on rheumatic disease in children. I hope you will realize the importance of investing a relatively small amount of support in the futures of my young patients, and the many children like them in the United States.

Many thanks for your help.

Sincerely,

JANE SCHALLER, M.D.,
Associate Professor of Pediatrics,
Director, Childrens Arthritis Clinics.

Enclosure.

STATEMENT OF DR. JANE SCHALLER, ASSOCIATE PROFESSOR OF PEDIATRICS, UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE, SEATTLE; ATTENDING PEDIATRICIAN AND DIRECTOR, PEDIATRIC ARTHRITIS CLINIC, UNIVERSITY HOSPITAL; ATTENDING PEDIATRICIAN AND DIRECTOR, RHEUMATOID ARTHRITIS CLINIC, CHILDREN'S ORTHOPEDIC HOSPITAL; ATTENDING PHYSICIAN, ARTHRITIS CLINIC, UNIVERSITY HOSPITAL AND HARBORVIEW MEDICAL CENTER; CLINICAL SCHOLAR OF THE ARTHRITIS FOUNDATION; MEMBER UNIVERSITY OF WASHINGTON COUNCIL ON PLANNING AND PRIORITIES, EDITORIAL BOARD OF UNIVERSITY OF WASHINGTON MEDICINE AND HEALTH SCIENCES COMMITTEE ON EQUAL OPPORTUNITIES FOR WOMEN

Mr. Chairman and Members of the Committee: My name is Jane Schaller. I am a pediatrician and rheumatologist, an Associate Professor of Pediatrics at the University of Washington Medical School, attending pediatrician at University Hospital and Children's Orthopedic Hospital, director of The Arthritis Clinics at these hospitals, and attending physician at Harborview Medical Center. I am also pleased to state that I am one of three Clinical Scholars of The Arthritis Foundation which is of substantial assistance to my endeavors in arthritis.

I am honored to be here today to speak for the American Rheumatism Association Section of The Arthritis Foundation concerning the FY 1975 budget for the Arthritis Program of the National Institute of Arthritis, Metabolism, and Digestive Diseases (NIAMDD).

My principal area of concern is Juvenile Rheumatoid Arthritis—a very serious disease that many people do not even know exists. Much of my time is spent in caring for children afflicted with this disease which is one of the most common chronic diseases of children in the United States today. About a quarter million American children are estimated to have Juvenile Rheumatoid Arthritis—more children than have leukemia and other childhood malignancies, and two to three times the number of children with diabetes.

Juvenile rheumatoid arthritis can produce crippling, blindness, growth retardation and psycho-social disability. In rare cases it can also be fatal.

Although affected children can and do benefit greatly from early diagnosis and appropriate therapy and followup, there are very few medical specialists sufficiently expert in the recognition and management of this disease to whom these children and their parents can turn.

Nor is there any special emphasis given to research aimed at investigating the basic mechanisms and causative factors of this disease—information which is a prerequisite to any major change in the way in which this disease can be more successfully managed.

I would like, if I may, to tell you a few things about this disease, some things we have already learned about it which are improving the way we deal with it, some things we urgently need to know more about, and why we feel that this Committee's recommendations for medical research in arthritis and for the training of more researchers in the rheumatic diseases are so important to enable us to help tens of thousands of children and their anxious parents.

Rheumatoid arthritis is a disease or a group of diseases characterized by inflammation of synovial tissues, the lining tissues of the joints. When joints become inflamed in rheumatoid arthritis they become swollen, sore or even painful, stiff, and limited in mobility.

Joints may become deformed, that is crooked or immobile, if the inflammation is very severe, or if there is inadequate attention to joint function early in the history of this disease. Joints may become destroyed and permanently disabled if the inflammation in the joints lasts too long before medical treatment is started.

Needless to say, limbs with joints affected by rheumatoid arthritis will not work well. If leg joints are affected, the patient will limp or have difficulty walking. If arm joints are affected, there will be a decrease in hand and arm function. Joints of the neck and jaw may also be affected, causing stiffness and pain on head and mouth movements.

It is obvious that a chronic disabling and painful disease such as rheumatoid arthritis will have a great impact on the affected individual and on his or her quality of life.

Juvenile rheumatoid arthritis may begin in several dissimilar ways, and may be difficult to distinguish in its early stages from other diseases with somewhat common symptoms. Correct diagnosis of juvenile rheumatoid arthritis requires the eye, hand and mind of the trained rheumatologist in order to differentiate the rheumatoid child from one with rheumatic fever, leukemia, rubella polyarthritis, and other infections which cause high fever, rash, tiredness and depression.

In about 20 per cent of affected children the disease begins with prominent, often alarming systemic symptoms of high fever, rash, enlarged liver and spleen and lymph nodes, inflammation of the lining about the heart (pericarditis) and the lungs (pleuritis), abdominal pain, anemia, and high white blood cell counts. Affected children also have inflammation of joints, although the joint complaints may be overlooked initially because of the severity of the overall illness.

There are several pitfalls in management of children with this type of juvenile rheumatoid arthritis. First of all, as has been noted, there may be failure to recognize the disease in its early stages. Mistaken diagnoses such as leukemia and infectious diseases are quite common. Secondly, there may be over-treatment of the systemic symptoms with dangerous drugs which can create more severe problems with drug side effects than would the disease itself. Thirdly, because medicine continues to emphasize the problems of acute diseases, there may be a failure to realize that the worst problem for children with this type of juvenile rheumatoid arthritis lies in *chronic* arthritis and that the joints must be carefully tended to if unnecessary crippling is to be avoided.

A second group of children, about 40 percent of all those with what we call juvenile rheumatoid arthritis, are affected by a relatively mild form of the disease which *concerns* only a few joints. These children, however, are at risk for another serious complication of this disease, iridocyclitis, or inflammation of the eyes. This damaging chronic eye disease will strike about 30 percent of children with few-joint (pauciarticular) arthritis at unpredictable times during the first ten years of their disease. Patients must be under constant surveillance for this eye disease because it is not associated with any early clinically recognizable cues to its presence. Visual loss resulting from this eye disease is a common cause of disability in juvenile rheumatoid arthritis. Some children are left permanently blind.

A third group of children, representing another 40 percent of children with juvenile rheumatoid arthritis, have a form of the disease which affects many joints but which is not associated with prominent systemic disease. This type of arthritis resembles rheumatoid arthritis as seen in adults. A few of these children have rheumatoid nodules and positive tests for rheumatoid factors and have severe progressive disease like severe adult onset rheumatoid arthritis.

Juvenile rheumatoid arthritis is only very rarely a fatal disease. Those who are damaged by the disease, therefore, live on as disabled human beings. We have learned in recent years that the prognosis for children with rheumatoid arthritis is much better than was previously supposed. With adequate care during periods of active disease, at least 75 percent of affected children will eventually get well with no serious disability. Nonetheless, the disease may be long lasting, is extremely unpredictable in the individual patient, and may certainly be discouraging and painful for patient and family alike. Most affected patients have either long lasting disease which can be satisfactorily controlled with medications and goes into eventual remission, or episodic disease which comes and goes but ultimately remits.

Of pressing concern is that 20–25 percent of the 250,000 children with arthritis—some 50–60,000 children—are afflicted with a severe progressive form of the disease which does *not* remit, is incompletely controlled by the best medical care, and results in severe disability.

The ultimate morbidity of juvenile rheumatoid arthritis is the result of several different factors:

1. There may be progressive damage from long-lasting and severe inflammation in the joints or the eyes. Unfortunately, in our current state of ignorance, we do not know the basic causes of inflammation in rheumatoid arthritis, and therefore we do not have any specific cures or ways of interrupting the process completely. We do have a number of drugs which are usually effective in quieting down inflammation, but none are curative.

2. There may be residual damage which persists after the period of active disease has ended. Several different kinds of residua can remain: (a) damage to joints or deformities of joints, (b) damage to eyes from iridocyclitis, (c) iatrogenic damage related to the use of drugs with permanent side effects, and (d) psycho-social invalidism resulting from the impact of a chronic disabling illness on the developing child and on his family.

Good medical care can play a significant role in preventing all of these kinds of residual damage from juvenile rheumatoid arthritis. Early attention to joints, optimum drug therapy, and good physical and orthopedic therapy can prevent the occurrence of joint deformities which might otherwise outlast the period of active disease. Early recognition and therapy of iridocyclitis can hopefully prevent scarring in the eyes with resultant loss of vision. Better education of physicians should lessen the use of dangerous drugs with permanent side effects. Careful attention to the whole child and his family with awareness of the problems which chronic illness can create can help to lessen the psycho-social impact of the disease.

WHAT WE HAVE LEARNED ABOUT JUVENILE RHEUMATOID ARTHRITIS

We have learned a great deal about the clinical manifestations of juvenile rheumatoid arthritis and about its natural history. From the study and follow-up of large groups of patients in several arthritis centers, which The Arthritis Foundation has helped finance, we have learned that the prognosis of the disease is relatively good and that 75 per cent of children will eventually get well. How- etiology of rheumatoid arthritis in general because of the readily distinguishable painful and very expensive, and that the outcome in the individual patient is generally unpredictable. Although most patients do get well in substantial number, in some the disease extends into adulthood, perhaps for a lifetime This kind of knowledge has pointed out the importance of conservative therapy in juvenile rheumatoid arthritis and the necessity of avoiding dangerous drugs, since many patients would get well in time with less severe measures.

In studying patients with juvenile rheumatoid arthritis, it has become apparent that there are several subgroups of the disease which may in fact represent different disease processes. As described previously, in about 20 per cent of the children affected, the disease is characterized by prominent systemic manifestations. These children do not appear to have serological abnormalities found in other kinds of rheumatoid arthritis, and this type of disease affects more boys than do other types of rheumatoid arthritis.

About 40 per cent of patients have few joints involved. As noted above, this type of disease is associated with iridocyclitis. The children who get iridocyclitis generally have positive tests for antinuclear antibodies, a serologic abnormality which is detectable in the blood. Systemic-type juvenile rheumatoid arthritis and

pauciarticular juvenile rheumatoid arthritis with iridocyclitis occur only very rarely in adult patients.

The third subgroup of juvenile rheumatoid arthritis, where the arthritis affects multiple joints, resembles that type of rheumatoid arthritis which occurs in adults.

The differentiation of these subgroups of disease is useful in diagnosis and therapy of patients and may also provide some insight into basic disease mechanisms.

A number of studies have been made concerning serological fiadings in juvenile rheumatoid arthritis. Rheumatoid factors (aatibodies reactive with gamma globuiin) are rarely detectable in children with rheumatoid arthritis by the same methods whieh will show these antibodies in about 80 per cent of affected adults. The occurrence of rheumatoid factors in children with rheumatoid arthritis appears to be associated with age at disease onset, although no one understaads this curious phenomenon at present. The antinuclear antibodies, a family of antibodies which react with varions nuclear constituents, are present in about one third of children with pauciarticular and polyarticular JRA, but are rarely found in children with systemic JRA. Antinuclear antibodies have been shown to be present in most children with chronic iridocyclitis and appear to be a useful test in predicting which children are at risk to develop eye disease. The occasional association of chronic arthritis, resembling juvenile rheumatoid arthritis, with various iaimune deficiency states, particularly in indlviduals who lack gamma globulin and the capacity to make normal antibodies, raises the question of whether a defect of the immune system may underlie some instances of rheumatic inflammation.

Many studies are being made trying to uncover the basic eauses of synovial inflammation in rheumatoid arthritis. Most of this work has been concerned with adult onset of the disease. Two main liaes of endeavor are the search for a possible viral or other infections agent as the basic cause of the synovial inflammation, and studies of the involvement of the immune system in prepetuating the inflammation in synovial and other tissues. Few studies have been made concerning synovial inflammation in children with rheumatoid arthritis. The absence of classic rheumatoid factors in most chi'drea with rheumatoid arthritis is of interest since rheumatoid factors have been implicated in the perpetuation of synovial inflammation in adults.

An exciting recent advance has been the association of tissue-type HL-A antigen W27 with the disease ankylosiag spoadylitis. Recent studies have indicated that this antigen may also be common in children with rheumatoid arthritis.

Considerable experience has been gained concerning therapeutic aad reconstructive orthopaedic surgery in children with rheumatoid arthritis. It has been established that although surgical removal of the inflamed synovium (synovectomy) may be of value in the occasional child, synovectomy does not appear to be curative in juvenile rheumatoid arthritis. Experieace in the total replacement of damaged joints, particularly hip joints, in adults with rheumatoid arthritis is now being extended to late teenagers and young adults who have iacurred severe disability from the hip disease of juvenile rheumatoid arthritis.

WHAT WE NEED TO KNOW ABOUT JUVENILE RHEUMATOID ARTHRITIS

Much more knowledge concerning the mechanisms of the iaflammatory process is needed. Until we better understand the steps which take place in the pathological process of inflammation, no specific drug therapy can be designed which will effectively interrupt the disease process.

The research for a possible infectious agent as the cause of synovitis, and further clarifications of the roles of immune mechanisms in allowing and perpetuating synovial inflammation must continue.

Virtually nothing is known of basic mechanisms underlying indocyclitis, or the fevers and other extra-articular manifestations of systemic juvenile rheumatoid arthritis. Studies in juvenile rheumatoid arthritis may offer insights into the etiology of rheumatoid arthritis in general because of the readiiy distinguishable subgroups of disease and the distiact possibility that more than one basic disease exists in this group.

Searches for genetic or tissue markers, such as the W27 HLA antigen, are of great potential value in sorting out different disease subgroups which may exist.

More research is needed into developing effective drug therapy for children (and adults) with rheumatoid arthritis. Our therapy today for rheumatoid arthritis is significantly better than it was ten or twenty years ago, but it continues to be less than satisfactory. It is largely palliative rather than curative or preventive. Therapy can be only partially satisfactory until we understand the underlying mechanisms of disease.

Epidemiologic studies may help us to understand the basis of juvenile rheumatoid arthritis. For instance, is this disease linked to ankylosing spondylitis? to adult rheumatoid arthritis? Is there any evidence that it is genetically determined? Is it determined by the environment? Are there specific genetic markers (such as the histocompatibility antigens) which might be identified in individuals with the disease?

The role of orthopaedic surgery in the treatment and rehabilitation of children with rheumatoid arthritis is an important one. We know little as yet about joint replacements in young individuals and about orthopaedic measures to correct joint deformities (such as contractures) which have occurred. Important work also remains to be done in the field of physical therapy concerning physical measures (such as exercises and splints) which might be effective in preventing deformities.

There is a need for investigation of the psycho-social aspects of chronic childhood diseases such as juvenile rheumatoid arthritis. Many patients are left with unnecessary invalidism caused by the impact of chronic disease on the social and emotional adaptations of the growing child. Family units can also suffer psycho-social problems secondary to the serious illness of one of their children. We know little of ways to identify and help such individuals who are at risk for this important and often neglected cause of potentially permanent disability.

THE NEED FOR TRAINED SPECIALISTS IN RHEUMATOLOGY

Vitally important for the proper care of children with rheumatoid arthritis and other rheumatic diseases is the presence of enough specialists trained in children's rheumatology to care for them. A shortage of such specialists already exists in this country. According to the American Rheumatism Association, there are only 33 pediatric rheumatologists in the United States. Since the training of future specialists is largely dependent on the number of medical school faculty available who are trained in this specialty themselves, and since the training grants which produced these specialists for medical school research teams have been drastically curtailed in the past few years, the future certainly does not look very bright in this regard.

I might add that a shortage of doctors trained to care for adults with rheumatic diseases also exists today in the United States. A manpower survey conducted by The Arthritis Foundation in 1972 indicated that about four and one-half times the current number of rheumatologists were needed as of that date to provide adequate care for patients with rheumatic diseases in this country.

If funds for training specialists to staff the faculty of our medical schools and our research laboratories continue to diminish there will be obviously more severe shortages of medical specialists in the future than there are now. Both patient care and medical research will suffer tremendously especially insofar as arthritis is concerned since rheumatology is such a new specialty.

SUMMARY

We now know quite a lot about juvenile rheumatoid arthritis and about its natural history. However, we know very little about its basic mechanisms. We have no specific curative therapy, and with currently available methods we are unable to control the disease in some patients. Many basic answers about disease mechanisms are needed before any truly effective therapy can be found. We need more researchers interested in exploring these questions, and we need more physicians trained in the care of children with rheumatoid arthritis. It certainly seems to me that a quarter million arthritic children represent a major challenge. It is impossible to add up all the pain, disability and discomfort that this disease represents to these children, and the anguish and hardship that it represents to their families. In fact, it is impossible to assign any value to a child except to say that children are our most important natural resource. A happy productive child is beyond any value we could place.

I suggest to the members of this Committee that it would be appropriate to count juvenile rheumatoid arthritis among this nation's most serious medical

problems, along with rheumatoid arthritis in adults which affects 5 million Americans, degenerative joint disease and gout which together affect 13 million adults, and other rheumatic diseases such as systemic lupus erythematosus which also plague a significant number of our citizens.

These diseases taken together constitute one of the largest health problems in our country today. Before we can improve our limited help to these patients, we need to know the basic causes and basic mechanisms of the diseases. Such answers will come only through research and through careful attention to large groups of patients by knowledgeable physicians. There are some very dedicated physicians and scientists interested in these problems, represented by the American Rheumatism Association of The Arthritis Foundation. Research in these fields has been advancing rapidly in recent years and it is probable that with adequate support further advances will be made. It should be noted that advances in the field of rheumatology will also be advances for medicine in general, since the basic processes involved in rheumatic diseases are shared by a number of other diseases: infectious diseases, cancer, and various immunologic disorders, to name only a few.

In this country today, unfortunately, we have no adequate alternative sources of funding for medical research than the Federal government. The private sources which support the training of medical research specialists in rheumatology such as The Arthritis Foundation and the Helen Hay Whitney Foundation, although they are now funding more post doctoral Fellows in Rheumatology than is the Federal government, are inadequate for the size of the task.

We would like very much to be of more help to our patients, children and adults alike. We feel that their cause is a worthy one, and we feel that our government must remain ever mindful that the quality of life of its citizens is a very important matter indeed. We are grateful to this Committee for its past support, and we hope that you understand how vital these matters are for our patients and for our society and will act accordingly.

The accompanying FY1975 budget recommendations for the Arthritis Program of The National Institute of Arthritis, Metabolism and Digestive Diseases are, I believe, realistic and conservative.

The total requested is slightly over $1.00 per arthritis victim. I cannot believe that such a modest amount of money could be considered too great to invest in the futures of my young patients and others like them.

I thank you, Mr. Chairmen, and Committee members for your courtesy.

[Whereupon, at 4:55 o'clock, p.m., the subcommittee adjourned.]

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